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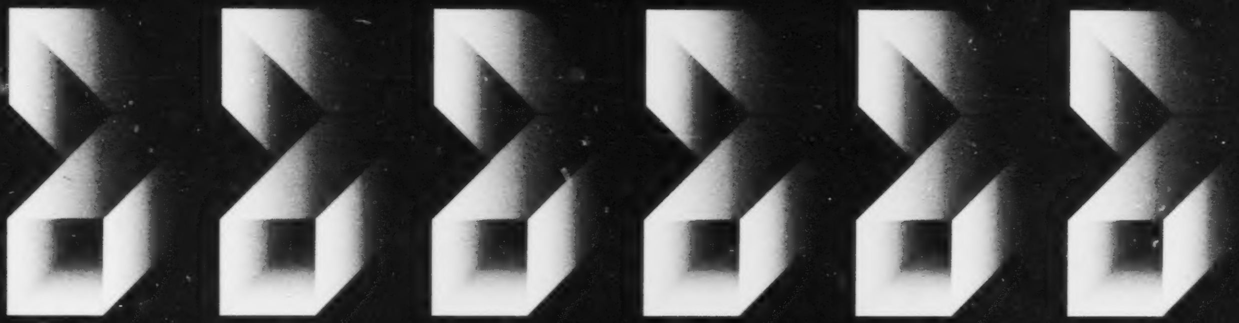

EVALUATION OF THE NATIONAL AIDS STRATEGY - PHASE II

DRAFT TECHNICAL REPORTS - VOL. 2
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MISSION STATEMENT

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 3:
Background Paper on Epidemiology of HIV/AIDS in Canada

September 2, 1997

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TABLE OF CONTENTS

PREAMBLE vi

1 BACKGROUND 1

1.1 Context: Evaluation of NAS-II 1
1.2 Objectives and Components of the National AIDS trategy 3
1.3 Problems in Associating Changes in the Epidemic with the Implementation of NAS-II 4

2 AIDS IN CANADA 1985 TO 1996 IN RELATION TO NAS-II 17

2.1 Number of AIDS Cases: The Total Burden of AIDS on Canadians 17
2.2 AIDS Incidence: Relative Burden of AIDS on Canadians 24
2.3 AIDS-Related Mortality 30

3 HIV IN CANADA 1985 TO 1996 IN RELATION TO NAS-II 37

3.1 Number of HIV Infections: Total Burden of HIV on Canadians 37
3.2 Summary: What this Tells Us About HIV in Canada Over the Period of NAS-II 44

4 SUMMARY AND CONCLUSION 45

4.1 Summary Statement 1: Overall Epidemic and Burden on Canada 45
4.2 Summary Statement 2: The Public Health Threat 46
4.3 Summary Statement 3: Potential Effects of NAS-II on the Epidemic 46
4.4 Conclusion 47

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PREAMBLE

This document is intended as a non-technical background paper to the evaluation of the National AIDS Strategy, Phase II (NAS-II). Its objective is to describe the evolution of HIV/AIDS in Canada since the beginning of the epidemic, but with particular attention to the time period and the population groups where NAS-II effects could have been felt. Because the epidemiologic methods used to collect, analyze, correct and interpret HIV and AIDS information are so new, there is naturally controversy among epidemiologists about which are acceptably rigorous. In this report, we have chosen to rely on published information which has passed rigorous review processes inside its sponsoring organizations and in external peer review. For many of these data, we are especially indebted to the Laboratory Centre of Disease Control of Health Canada.

Note also this report concentrates on adult populations, that is Canadians aged 15 years or older. This is first, because children were not a focus of NAS-II, and second, because infection in childhood is a direct function of infection among adults[1].

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1. United Kingdom Overseas Development Administration, Communicable Disease Surveillance Centre (1996). Sexual Health and Health Care: HIV, AIDS and Sexually Transmitted Infections. Global Epidemiology, Impact and Prevention. London: ODA.

CHAPTER 1

BACKGROUND

1.1 Context: Evaluation of NAS-II

Acquired Immunodeficiency Syndrome (AIDS) and the virus which causes it, Human Immunodeficiency Virus (HIV) have been present in Canada since 1978, although systematic reporting was not established until 1982. As of April 15, 1997, 14,836 cases of AIDS and 10,837 deaths have been reported[2]. As of the end of 1996, an estimated 50,000-54,000 Canadians had ever been infected with HIV and 36,000-42,000 were living with HIV infection[3].

In 1990, the federal government implemented the National AIDS Strategy, Phase I. This was followed in 1993 by Phase II, which is funded from 1993 to 1998. A preliminary announcement has been made for a Phase III of the Strategy.

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[2] Health Canada, Laboratory Centre for Disease Control (LCDC), Quarterly Surveillance Update, May, 1997. Note that the most complete data on HIV/AIDS in Canada, with breakdowns by region and risk factors, were available only up to the end of December 1996 at the time of the evaluation. Wherever possible, the most recent summary data (May, 1997) are cited, but in some cases the December 1996 data are used.

[3] Health Canada, LCDC, Epi Update, May, 1997.

An evaluation of the continued relevance, success and cost-effectiveness of the NAS-II was planned for 1997. In the context of that evaluation, it is essential to examine how the epidemic has evolved since concerted government intervention began. If the National AIDS Strategy has been successful in building or supporting an infrastructure that can slow the epidemic, its effects should eventually be visible, over and above naturally-occurring changes or changes effected by other agencies, in terms of reduced transmission of HIV and better, longer lives for those living with AIDS-related illness. This paper brings together information from several sources to look at how the epidemic has evolved and how its course may have been altered during the period covered by NAS-II, and perhaps due in part to the actions of NAS-II and its partners. This information can also help examine how appropriately NAS-II was targeted.

However, a number of factors limit our ability to discern whether or not NAS-II has had any effect on HIV/AIDS in Canada. After a brief description of NAS-II activities, these factors are explained in the rest of the first chapter. They are important because they affect how confident we can be in our conclusions regarding the impact of the Strategy on the disease.

In the second chapter, we examine the evolution of AIDS in Canada, that is, the number of people who have become ill with AIDS or have died. The third chapter looks at HIV infection in Canada over the period covered by NAS-II. In both of these chapters, we look at the epidemic from two perspectives: first, in terms of the overall burden of illness on Canada caused by HIV/AIDS, and second, by comparing within regions of Canada and with other countries to see how well Canada and its regions fare in relative terms.

Our final chapter synthesizes the information from the previous chapters and makes some summary statements about HIV/AIDS in Canada during the period of NAS-II. Keeping in mind the factors which limit our confidence in the conclusions, these statements distinguish between what seems relatively certain, what is likely, and what is only possibility. Finally, this chapter acknowledges that data are never neutral but rather are always proposed and interpreted within a particular set of values and interests. We acknowledge this by providing the most plausible competing interpretations of each summary statement.

1.2 Objectives and Components of the National AIDS Strategy

Phase I of the National AIDS Strategy emphasized both partnership among governments and other organizations, and balance between prevention, search for effective treatments, and care. During 1990 to 1993, the Strategy supported work by the federal government in the following areas:

- ☐ *education and prevention*;
- ☐ *research* on epidemiological, social, and cultural factors, on treatments and therapies, on basic immunologic and virologic processes, on development of vaccines;
- ☐ *care, treatment and support* for those living with HIV/AIDS;
- ☐ *support to non-governmental organizations;* and
- ☐ *coordination and collaboration.*

In 1992, the federal government once again conducted broad consultations to validate the framework for action of Phase I of the Strategy. These consultations suggested that this framework was valid, and were followed in March 1993 by the announcement of Phase II of the National AIDS Strategy (NAS-II)[4].

The National AIDS Strategy, Phase II reaffirmed the federal commitment to address HIV and AIDS in Canada in a concerted, collaborative fashion. Three objectives of Phase II, unchanged from Phase I, are:

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[4] Health and Welfare Canada (1993), National AIDS Strategy, Phase II: Building on Progress.

- ☐ stop the transmission of HIV;
- ☐ search for effective vaccines, drugs and therapies; and
- ☐ treat, care for and support people infected with HIV, their caregivers, families and friends.

A fourth, overarching goal is to:

- ☐ implement NAS Phase II activities effectively.

Phase II of the National AIDS Strategy identified several vulnerable populations to be specifically targeted in prevention and treatment activities and programs. These are: men who have sex with men, injection drug users and their sexual partners, aboriginal people, street-involved youth and populations in correctional facilities.

Given its goals, if NAS-II has had an impact on the epidemic, changes should be seen in both the number of Canadians who have become infected with HIV since the Strategy was implemented, and in the health and longevity of those who were already infected before NAS-II began.

1.3 Problems in Associating Changes in the Epidemic with the Implementation of NAS-II

In this section, we outline the major problems in associating changes in the epidemic with the implementation of NAS-II. Readers should be aware that it is only after individuals who are infected with the human immunodeficiency virus have had a positive test result on an HIV test, that they can be classified as HIV cases. They may remain free of symptoms for many years, but once a certain specified set of symptoms appear (according to standardized definitions[5]), they are classified as AIDS cases. The problems outlined below may apply to either or both of HIV cases and AIDS cases.

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[5] Revised Canadian Surveillance Definition of AIDS, Canada Communicable Diseases Report, 1993, 19, 116-117.

(a) Measurement and Classification Problems

Even if NAS-II has had effects on the epidemic, they may have been obscured by a number of factors. The first type of factor, discussed in this section, are related to how AIDS and HIV cases are identified and counted.

Definition of AIDS

As more and more has become known about the disease and as treatments have become available which prevent the appearance of some opportunistic infections, the **criteria for defining clinical cases of AIDS have changed**. In Canada, a modified definition was adopted in 1993[6], adding three AIDS-defining conditions, and all current reporting uses it. However, at some point in the future the definition may again be revised and may include cases previously not counted in the reporting systems[7].

Reported Cases of AIDS

While public health laws require that all cases of AIDS be reported by the diagnosing physician or laboratory running the test to central public health authorities, there are some important problems with the numbers that are actually obtained from those reports.

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[6] Revised Canadian Surveillance Definition of AIDS, Canadian Communicable Diseases Report, 1993, 19, 116-117.

[7] Montaner, J., Le, T., Hogg, R., Rickettes, M., Sutherland, D., Strathdee, S., O'Shaughnessy, M., Schechter, M. (1994). The changing spectrum of AIDS index diseases in Canada. AIDS, 5(8), 693-696.

Under-reporting of AIDS cases can occur because of cases that have been diagnosed but not yet reported (reporting delay), and because of cases that will never be reported. Reporting delay, between the time the diagnosis is made and the information reaches the central authorities, has been shown to vary in Canada between several weeks and 13 years. Half of diagnoses are reported within nine months of the diagnosis date[8]. Correction techniques have been developed to take these two factors into account, and now in most cases Canadian data are reported after having been corrected for reporting delays. However, it is not currently possible to correct completely for never-reported cases using only the AIDS case data, without external corroborating information.

AIDS-Related Deaths

Data on AIDS-related deaths come from death certificates completed by physicians and forwarded to some provincial vital statistics departments. The **data on AIDS-related deaths are never 100 per cent reliable** because a certain proportion of death certificates, for AIDS as for most all other causes of death, are incomplete or erroneous. Studies in other areas also have shown that certain socially sensitive causes of death are systematically under-reported on death certificates (suicide, alcoholism) so this can expected to be a factor in AIDS-related death as well. In addition, it may take time for physicians to learn about and recognize AIDS-related causes of death. Before they do, they may erroneously attribute deaths to other causes. A final complication is that as new treatments for the disease emerge, the illnesses that actually cause death will change over time, and there may be lags between the time that these changes begin to happen and that the reporting systems recognize them as AIDS-related deaths.

[8] Health Canada, December 1996; Annual Report on AIDS in Canada.

Reporting of HIV Infection

The data on the extent of HIV infection among Canadians are less "solid" than those for AIDS. This makes both estimation of the cases prevented and the projection of the number of expected AIDS cases very difficult. Health Canada has recently released the first National HIV Database Surveillance Report, using data from a surveillance system established in 1993[9].

A main reason why HIV data are less solid than AIDS data is because there is **no national standard for HIV reportability**. Public health laws concerning diseases to be reported to public health authorities vary province by province. Currently, HIV infection is a not reportable condition in three Canadian provinces, accounting for roughly 50 per cent of all cases. Data from these provinces must therefore be estimated from other sources.

Estimating HIV Infection

It was decided very early in Canada's AIDS strategy that to encourage people to come forward and be tested, testing must be completely anonymous. Anonymous testing has had the desired effect of increasing testing, but it has the drawback that if people get tested more than once — and many do — there are **duplicate test results** in the data. Elimination of duplicates without breaches of confidentiality requires sophisticated database management techniques which have only recently been available. Data prior to 1995 are therefore likely to be somewhat inflated by duplicate tests, although corrections are made as much as possible[10].

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9. Health Canada (1996), HIV in Canada: Surveillance Report for the Period 1985 -1995.

10. Health Canada (1996), HIV in Canada: Surveillance Report for the Period 1985-1995.

Estimates of HIV infection obtained from statistical estimations based on AIDS cases reported to public health authorities can be compared with data from anonymous surveys where a large number of individuals' HIV status is tested in the same period of time. These data are less likely to have duplicates than data reported to public health authorities, but are more subject to sampling bias because of the difficulty reaching marginalized groups. In one such comparison between these two sources of data on HIV prevalence, results were comparable for the largest group (men), but varied by technique for women and children[11]. This suggests that current estimates of HIV infection remain approximate, especially in groups with lower infection rates.

Accessibility of HIV Testing

The number of people having HIV tests, and therefore the extent to which the number of people testing positive approaches the true infection rate in the tested and untested population, is partly dependent on the availability of the test. **Tests have become more accessible** over the last few years (perhaps partly due to government intervention), so the rate of testing may have changed. However, in some areas (for example, in small towns or on reserves), **barriers to testing** are still present because individuals are concerned about confidentiality. In these groups, testing rates may be lower, resulting in a greater inaccuracy in the measured rate of infection than in other groups who can seek testing more readily.

Overlap Between HIV and AIDS Data

Because of how the data is reported, it is currently impossible to tell if an individual has been **counted in both the HIV and AIDS databases**. This means that the total number of expected AIDS cases will be lower that what would be expected by simply adding up the number of HIV infections and the number of AIDS cases[12].

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[11] Remis, R.S., Vandal, A., Leclerc, P., Février 1996, La situation du SIDA et de l'infection au VIH au Québec, 1994, Centre québecois de coordination sur le SIDA.

Exposure Categories

HIV has not spread evenly throughout the Canadian population. Rather, it has been concentrated in some groups who are characterized by specific transmission behaviours. These have been termed exposure categories (and are sometimes referred to as risk factors). While these exposure categories are critical to following the progression of the epidemic in specific population groups and to targeting interventions for them, they are not always easy to define. The exposure categories currently in use are: men who have sex with men (MSM), injection drug users (IDU), men who have sex with men and who are injection drug users (MSM/IDU), heterosexual contact with a person from an endemic[13] country, heterosexual contact with a person at risk, occupational exposure, recipient of blood, recipient of clotting factor, perinatal transmission and no identified risk factor (NIR). Some of these categories are **not mutually exclusive** (for example, injection drug user and heterosexual contact with a person at risk), and a set of rules has been established so that each case is classified only once[14]. However, this may lead to distortions in the patterns observed. Changes to the surveillance system concerning exposure categories are currently being made, and may affect interpretation of prior data.

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[12] Health Canada, HIV in Canada, 1996.

[13] An endemic country is one in which the primary mode of transmission is through heterosexual contact.

[14] LCDC, Quarterly Report, February 1997.

Summary: Measurement and Classification Problems in Associating Changes in the Epidemic with the Implementation of NAS-II

The above list of measurement problems indicates that there is still some uncertainty about the evolution of the HIV/AIDS epidemic in Canada. This is troublesome for public health authorities and Canadians alike. However, considerable effort is and has been expended in Canada (much of it through NAS-II support) and worldwide to improve our ability to track the epidemic accurately and closely, and our knowledge is much more precise and complete than it was at the beginning of the epidemic.

(b) Problems Due to Change in the Epidemic

The second type of obscuring factors are related to changes that have occurred in the epidemic itself over time.

Waves of the Epidemic[15]

Since HIV/AIDS came to Canada in the late 1970's and early 1980's and well before the introduction of NAS-II, the patterns of infection have changed in successive waves. First to be affected were individuals from endemic countries where HIV is widespread in the general population, who were likely infected in their country of origin. The second wave of infection, probably strongest throughout the early to mid-1980's, affected men who have sex with men (homosexual and bisexual men). The third wave, affecting injection drug users, began to rise in the late 1980's and has risen markedly in the last few years[16]. These wave patterns complicate our ability to associate changes in the epidemic to government intervention, because we do not know if or when they have crested and begun a downturn on their own, that is, against what natural change in the epidemic we should be assessing effects of NAS-II. Moreover, the total number of people in these groups may have increased or decreased over time (e.g., injection drug users), so that the trends may partly indicate that there were simply more or fewer people available to infect.

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[15] This section is based on Remis, R.S., & Leclerc, P., November 1996: Portrait of the HIV/AIDS epidemic in Quebec, Centre québecois de coordination sur le SIDA.

Three other, smaller waves of the epidemic are also mixed in with the main waves. The first, the transmission of HIV through blood and clotting factors received in hospitals and transfusion services, was effectively stopped in 1985. Although many of these individuals will progress to an AIDS diagnosis within the next few years, much effort has been made to prevent new transmission from this source. However, two other secondary waves of infection are more recent and perhaps still increasing. Infections of children through pregnancy, delivery or breast-feeding are a secondary effect of increasing numbers of women being infected through the third wave, heterosexual transmission. These waves are more recent, and their full impact on AIDS rates has yet to be felt.

Increased Delay of AIDS Onset

A second way that the epidemic is changing is that the time between infection with HIV and onset of AIDS has been steadily increasing, probably in part because of new therapies and treatments coupled with earlier diagnosis linked to more accessible testing. As testing becomes easier and more accessible and as more effective treatments and therapies become available, these delays will likely continue to increase. While some of these improvements may be partly or largely due to activities supported by NAS-II, it would be erroneous to attribute all of them to the Strategy, since they may also be due to a number of other factors, such as development of new AIDS-delaying treatments (prophylaxis) outside Canada.

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[16] Health Canada, LCDC, Epi Update, May, 1997.

Increased Survival for People with AIDS

Finally, improved treatments for people with HIV/AIDS may have increased both their length and quality of life. While some of these improvements may be partly or largely due to activities supported by NAS-II, it would be misleading to attribute all of them to the Strategy. In some cases, these improvements have been the result of large joint international efforts to which Canadian scientists have contributed. Although of interest to assess the Canadian contribution, it would be difficult to isolate it from these collective efforts.

Differential Resistance and Susceptibility

International research suggests that the efficiency of HIV transmission (the likelihood that infection will occur given exposure) varies according to a number of factors, including route (from whom to whom and how), presence of other diseases, stage of HIV disease, and social and sexual practices[17]. According to some studies, HIV-infected people who are taking antiretroviral treatment are significantly less infectious than those not on treatment[18]. The expected rate of infection, against which

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17. Royce, R., Sena, A., Cates, W. et al. (1997) Sexual Transmission of HIV. New England Journal of Medicine, 336(15), 1072.

    United Kingdom Overseas Development Administration, Communicable Disease Surveillance Centre (1996). Sexual Health and Health Care: HIV, AIDS and Sexually Transmitted Infections. Global Epidemiology, Impact and Prevention. London: ODA.

18. Royce, R., Sena, A., Cates, W. et al. (1997) Sexual Transmission of HIV. New England Journal of Medicine, 336(15), 1072.

the effects of NAS-II prevention efforts should be measured, may be lower in some parts of the population than others or over time because of these factors and may therefore cause estimates of cases prevented to be inflated.

Other research suggests that people infected when they are younger take longer to develop AIDS after their HIV infection and live longer[19]. However, other groups, such as injection drug users, may have shorter life expectancies than other risk groups, thus obscuring the effect. As patterns of infection shift to younger people (see below), data on AIDS will show an improvement in outlook that is due to age rather than to the effects of NAS-II or other interventions.

Summary: Problems Due to Changes in the Epidemic

The changing nature of the epidemic makes it difficult to disentangle the effects of interventions from changes due to other reasons. In examining data on the evolution of the epidemic, we must always keep in mind that there are several possible explanations for each observed change.

(c) Introduction of NAS-I, NAS-II and Other Interventions

Finally, the nature of the intervention programs funded by NAS-II also complicates our ability to associate the Strategy with changes in the epidemic.

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[19] AIDS Clinical Care, 9(3), 27.

Effects of NAS-I and Other Interventions

Although NAS-I was in place from 1990 to 1993, and although most HIV/AIDS activity was at that time supported by it, no assessment was conducted of its possible impact on the epidemic. Because prevention activities may have delayed effects (e.g., high school sexual health education having effects on sexual behaviour in early adulthood), some NAS-I activities may have contributed to changes now being observed. In addition, many other interventions, led by provincial and non-governmental organizations, have been implemented independently but at the same time as NAS-II. Moreover, media attention in Canada, the U.S. and Europe has increased, raising awareness in the general population. These factors make the specific effect of NAS-II very difficult to isolate.

Possible Effect Windows

In looking for effects of NAS-II and other interventions, we need to look not only at the overall epidemic, but also at the groups that could have been affected by it at the time of its introduction. In industrialized countries, the median time between HIV infection and the AIDS diagnosis is about 10 years[20]. For this evaluation of NAS-II, this means that we must specifically examine how much transmission appears to have been prevented in NAS-II target group members not already infected before 1993 (NAS-II prevention objective) and how much HIV and AIDS treatments have improved outcomes for people already infected before 1993 and who have become infected since (NAS-II treatment objective).

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[20] United Kingdom Overseas Development Administration, Communicable Disease Surveillance Centre (1996). Sexual Health and Health Care: HIV, AIDS and Sexually Transmitted Infections. Global Epidemiology, Impact and Prevention. London: ODA.

Staggered Implementation

Although NAS-II was officially in place from 1993 to 1998, it did not abruptly begin to have potential effects in 1993. The partnership nature of NAS-II naturally resulted in staggered timing of the implementation of the various components in various regions. The search for impacts of NAS-II must also take into account that real exposure to NAS-II-related or -supported activities will not be equivalent across the country and across all groups.

Differential Effectiveness or Interaction of Components

NAS-II is composed of a number of different components delivered in partnership with or by a number of partners. Some of these components and partnerships may have been more effective than others. Groups exposed to the more effective components would be expected to have more benefit than those exposed to less effective components. The net effect of this differential effectiveness over the whole epidemic may mask the potentially strong effects for individual components, or potential negative or nil effects of others. Alternatively, some components might have had multiplier effects greater than the sum of their independent contributions. To the extent possible, NAS-II effects should be examined for each program component.

Dose-Response Effects

It may also be possible that effects on the epidemic will be observable only over some threshold level (intensity, frequency or duration) of intervention. Because of the ways decisions were made at regional and local levels and because of differing degrees of readiness and mobilization, some target groups for the National AIDS Strategy may have received different levels of intervention. Only some of these target groups may have received a sufficiently intensive intervention to get beyond the threshold for effectiveness.

Summary: Effects of NAS-I, NAS-II and Other Interventions

The above discussion shows that we must exercise caution in trying to identify precisely the impacts the National AIDS Strategy has had on the evolution of the epidemic in Canada. At most, we will be able to show that there is an association between the introduction of NAS-II and changes in the epidemic, but that those changes may also be, to an unknown extent, influenced by other factors. It is essential that interpretations of the data presented in the following chapters make no claims which cannot be supported by the evidence, but that the most likely hypotheses are clearly identified.

CHAPTER

2 AIDS IN CANADA 1985 TO 1996 IN RELATION TO NAS-II

2.1 Number of AIDS Cases: The Total Burden of AIDS on Canadians

(a) Cases by Sex

Exhibit 2.1 shows the total cumulative number of AIDS cases in Canada, from 1985 up to the end of 1996, for males and females older than 15 years. To this point and after adjustment for reporting delay, the total number of cases was 16,931. Far more men than women have been infected to date. The number of cases has risen steadily and sometimes sharply since 1985. Given the average ten-year lag between HIV infection and emergence of AIDS, most of these cases were probably infected with HIV at least several years before the introduction of the National AIDS Strategy Phase I or Phase II.

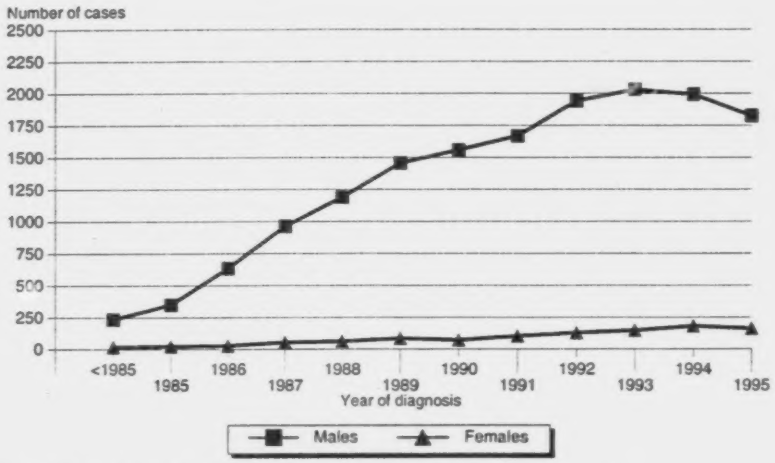
(b) Cases by Exposure Category

Looking at Exhibit 2.1 in relation to Exhibits 2.2a1 and 2.2a2, below, shows that the high number of AIDS cases among men is associated with transmission

EXHIBIT 2.1

Number of AIDS Cases, Adjusted for Reporting Delay

By Year of Diagnosis, Males and Females, Canada, Cases Diagnosed up to December 31, 1995



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

among homosexual and bisexual men. This category accounts for almost 80 per cent of all AIDS cases in Canada. The number of diagnoses per year in this category has declined from its peak of 1,210 cases in 1992 to 796 cases in 1995. The number of cases per year due to heterosexual contact with a person at risk increased to a peak of 189 cases in 1993 (males and females combined). The number of cases among injection drug users has also increased over this period, to a total of 549 cases in 1996. By the end of 1996, a total of 495 diagnosed adult AIDS cases had been infected through receipt of clotting factors or blood.[21]

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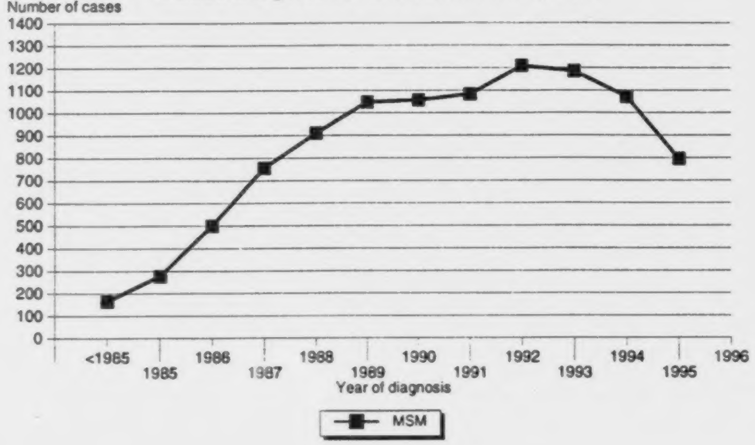
[21] Note that the number of transmissions of HIV through the blood supply, believed to be about 1,200 cases in total, greatly exceeds the reported AIDS cases who have receipt of blood products as a risk factor. Many people infected through the blood supply were never registered as AIDS cases, mainly because they died of other causes before they developed AIDS.

EXHIBIT 2.2a1
Number of AIDS Cases Adjusted for Reporting Delay, by Year of Diagnosis, Males

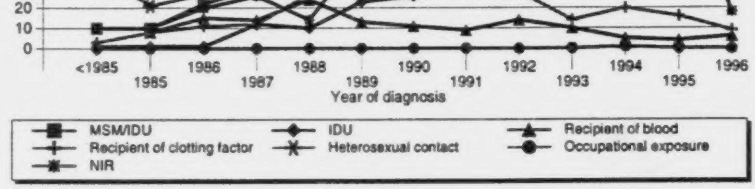
By Exposure Category, Canada, Cases Diagnosed to December 31, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

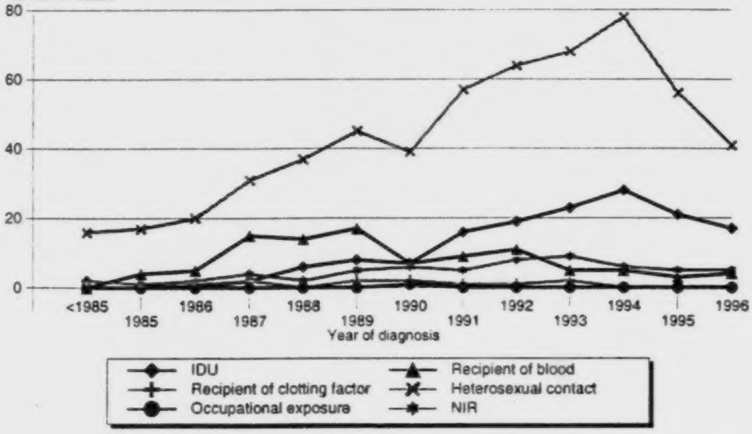
EXHIBIT 2.2a2
Number of AIDS Cases Adjusted for Reporting Delay, by Year of Diagnosis, Males

By Exposure Category, Canada, Cases Diagnosed to December 31, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

EXHIBIT 2.2b
Number of AIDS Cases Adjusted for Reporting Delay, by Year of Diagnosis, Females
By Exposure Category, Canada, Cases Diagnosed up to December 31, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada*. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

(c) Cases by Region

Exhibit 2.3 shows that AIDS cases are unevenly distributed across Canada. Up the end of 1996, 40 per cent of all AIDS cases were found in Ontario, 33 per cent were found in Québec, and 17 per cent were found in British Columbia. The provincial health systems in these provinces thus have a relatively greater burden in terms of caring for these individuals.[22] However, the number of AIDS diagnoses per year seems to have stabilized or begun to decline in these three provinces since about 1993. In the other regions of Canada (Alberta, Prairies-Territories, and Atlantic), this pattern of cresting and decline is not as apparent. This could be because the small number of cases makes random variation by year hard to separate from true trends, or because the waves of transmission have hit these provinces later. Migration between provinces and from smaller to larger cities (urbanization) may also affect these trends.

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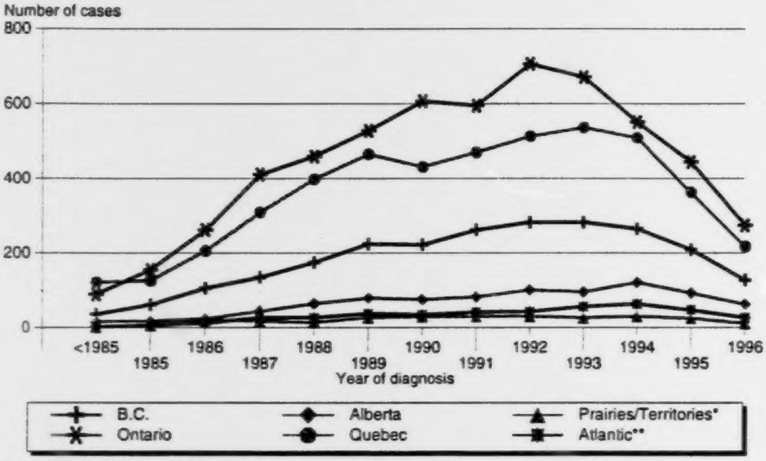
[22] Note that there are important differences between provincial reporting systems, making direct comparisons inappropriate.

EXHIBIT 2.3
Number of AIDS Cases, Adjusted for Reporting Delay,
By Year of Diagnosis and Region, Canada,
Cases Diagnosed up to December 31, 1996



* Includes Saskatchewan, Manitoba, Yukon, and Northwest Territories.
** Includes Newfoundland, Prince Edward Island, Nova Scotia, and New Brunswick.

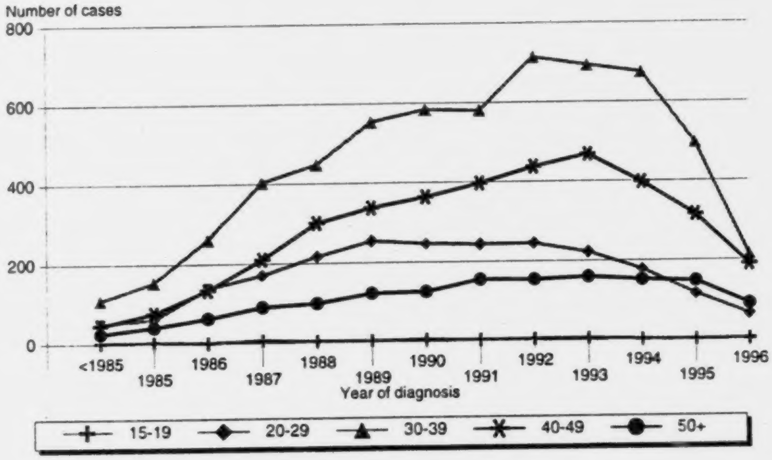
Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

(d) Cases by Age Group

In Exhibits 2.4a and 2.4b, the distribution of AIDS cases in men and women in different age groups is shown. From 1985 to 1996, most AIDS cases diagnosed in men were among 30 to 39-year olds and 40 to 49-year olds. These two age groups accounted for about 70 per cent of cases. Among women, these two age groups accounted for about 62 per cent of cases. Proportionately more women than men were diagnosed in the younger age category of 20 to 29 years old.

EXHIBIT 2.4a
Number of AIDS Cases

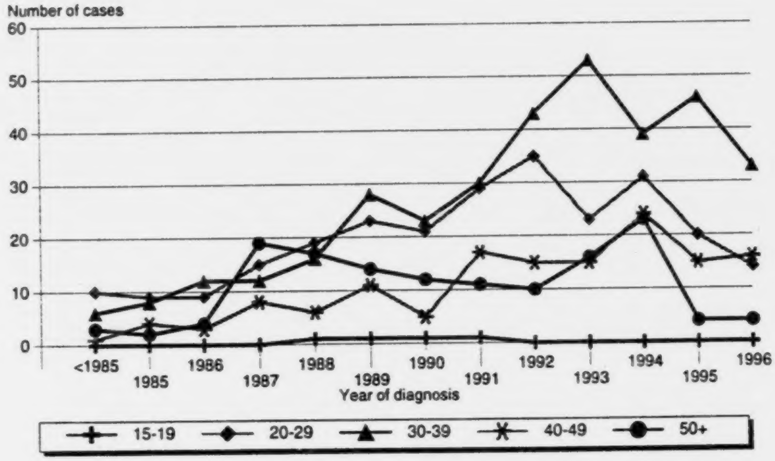
By Age Group and Year of Diagnosis, Males, Canada, Cases Diagnosed up to December, 31, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

EXHIBIT 2.4b
Number of AIDS Cases

By Age Group and Year of Diagnosis, Females, Canada, Cases Diagnosed up to December, 31, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

Keeping in mind the average delay of 10 years between infection with HIV and AIDS diagnosis, these data illustrate an important consequence of the fact that HIV/AIDS is largely a sexually transmitted disease. Higher rates of transmission occur during a phase of life when likelihood of partner change and risk-taking is greater, i.e., during adolescence and young adulthood. In other words, these age groups are particularly vulnerable to infection simply because of their developmental phase[23]. A second consequence is that the burden on society of fatal illness among youth is considered to be greater than that for older people, because of the larger number of potentially productive years lost and because of the care that they will not be able to give their children and their elderly[24]. The relatively higher proportion of younger women than older women among diagnosed AIDS cases is noteworthy in this respect, because these women are in their prime childbearing and childrearing years.

(e) AIDS Cases in the Aboriginal Population

Available data suggest that HIV infections are increasing among Aboriginal people[25]. As of May 1997, 232 cases of the 14,836 AIDS cases reported were among First Nations, Inuit or Métis people. Adjusted for reporting delay, the cumulative incidence of AIDS as of December 1996 among Aboriginal people was estimated to be 24 per 100,000.

This incidence is much higher than in the non-Aboriginal population, and is almost certainly an underestimate due to uneven or absent reporting of ethnicity in some provinces (41 per cent of reported cases lack ethnic information). Considering only AIDS cases with known ethnic status and not taking into account any changes in the size of the total Aboriginal population, the proportion of total AIDS cases among aboriginal people has risen from 1.4 per cent in 1984-89 to 3.6 per cent in 1993-96. Injection drug use is a major risk factor: 11.5 per cent of male Aboriginal AIDS cases have injection drug use as a risk factor compared to 2.8 per cent in non-Aboriginal AIDS cases. Forty-three per cent of female Aboriginal AIDS cases are injection drug users compared to 15 per cent of non-Aboriginal female cases. Aboriginal AIDS cases are also younger and more likely to be female than non-Aboriginal cases[26]. Aboriginal people are also overrepresented in populations at risk for HIV transmission, including prison populations and inner city injection drug users.

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[23] United Kingdom Overseas Development Administration, Communicable Disease Surveillance Centre (1996). Sexual Health and Health Care: HIV, AIDS and Sexually Transmitted Infections. Global Epidemiology, Impact and Prevention. London: ODA.

[24] United Kingdom Overseas Development Administration, Communicable Disease Surveillance Centre (1996). Sexual Health and Health Care: HIV, AIDS and Sexually Transmitted Infections. Global Epidemiology, Impact and Prevention. London: ODA.

[25] Health Canada, LCDC, Epi Update, May 1997.

2.2 AIDS Incidence: Relative Burden of AIDS on Canadians

In this section, total estimated numbers of AIDS cases are divided by population totals, in order to show the relative impact in different groups and regions.

(a) Incidence by Sex

In Exhibit 2.5, the annual incidence of AIDS (number of new cases per year, divided by the number of people in the relevant population in that year) is shown for males and females and both together from 1985 to 1995. These data show that overall, the annual incidence seems to have peaked in 1993, at 9.5 cases per 100,000 population. However, because there are far more cases in men than women, the overall trend in incidence is driven by the trend for men, which peaked at 18.0 cases per 100,000 population in 1993. In contrast, annual incidence in women has increased at least until 1994 and has not yet shown a similar decline.

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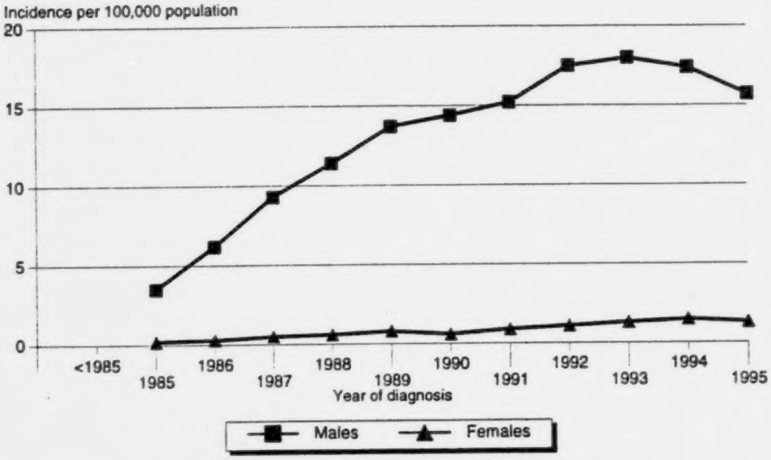
[26] Health Canada, LCDC, Epi Update, December 1996.

EXHIBIT 2.5
Annual Incidence per 100,000 of AIDS, Adjusted for Reporting Delay

By Year of Diagnosis, Males and Females, Canada, Cases Diagnosed up to December 31, 1995



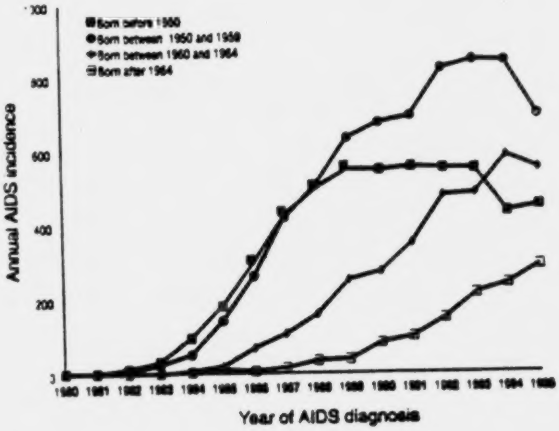
Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

(b) Incidence by Age Group

Exhibits 2.6a and b shows annual incidence for men and women by birth cohort, that is by categories of year of birth. This is another way of showing how the epidemic has affected different age groups. These data show that among men, annual incidence seems to have crested and begun to decline among those who were 20 or older at the start of the epidemic (around 1984). Among those men who were 19 years old or younger at the start of the epidemic, the annual incidence of cases began to increase more slowly but has not yet shown a decline like that seen in the older cohorts.

EXHIBIT 2.6a
Annual Incidence of AIDS Cases, Adjusted for Reporting Delay

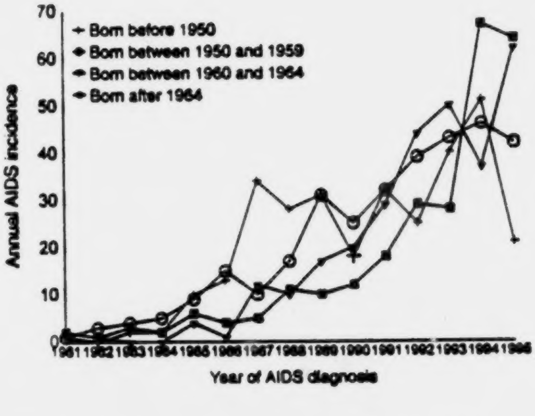
By Year of Diagnosis, and Birth Cohort, Males and Females, Canads, Cases Diagnosed up to December, 31, 1995



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada*. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

EXHIBIT 2.6b
Annual Incidence of AIDS Cases, Adjusted for Reporting Delay

By Year of Diagnosis, and Birth Cohort, Males and Females, Canads, Cases Diagnosed up to December, 31, 1995



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada*. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

Among women, the age patterns are less clear, partly because of the smaller number of cases. It seems, however, that annual incidence among women has generally increased among all age groups, but has had a relatively greater increase among women who were younger at the start of the epidemic.

(c) Incidence by Exposure Category

Because the total number of individuals in each exposure category (e.g., total number of injection drug users in Canada in a given year) is not precisely known, it is difficult to calculate the rate of infection of AIDS in each group. However, we can still examine the overall composition of the epidemic over time, by looking at percentage of cases in each exposure category. (Note, however, that this comparison of proportions does not take into account the decline in the overall number of cases.) These data, shown in Exhibit 2.7, show that proportion of cases who were men who have sex with men (excluding men who have sex with men and who are also injection drug users) declined from a high of 80.1 per cent of cases diagnosed in 1987, to 69.2 per cent of cases diagnosed in 1995. The proportion of cases diagnosed each year among injection drug users has increased over this period, from 3.2 per cent in 1985 to 14.2 per cent in 1995. Note, however, that this increase could be a reflection of an increase in the total size of the injection drug population. The proportion of cases diagnosed among those having heterosexual contact with a person at risk has also risen steadily over the past five years, from 9.8 per cent of cases diagnosed in 1991 to 16.6 per cent of cases diagnosed in 1995. Because of this increase in heterosexual transmission[27], the number of cases among women and children has also continued to increase.

Over and above these changes in the proportion of cases in each exposure category over time, age seems to be a factor in whether the infection rate has

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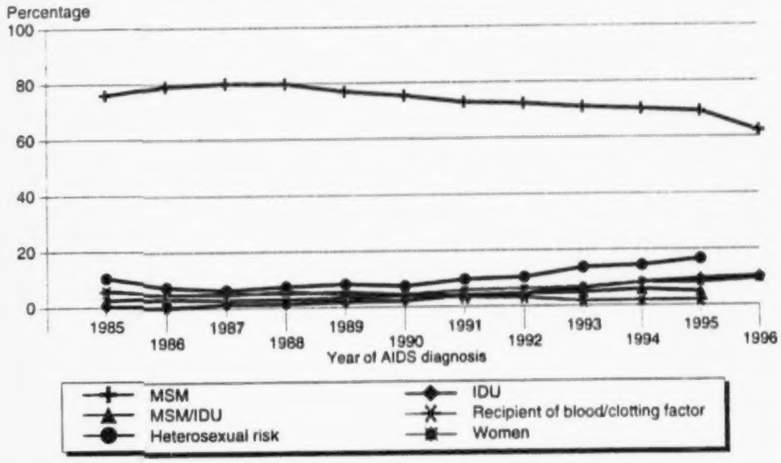
[27] Note that the criteria for defining heterosexual contact with a person at risk are applied differently in different provinces.

EXHIBIT 2.7
Percentage Distribution of AIDS Cases, (Adjusted for Reporting Delay)
By Selected Exposure Category, Canada, Cases Diagnosed up to December 31, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

crested and begun to decline. For the three main exposure categories (men who have sex with men, injection drug use, and heterosexual contact with a person at risk), annual incidence rates (number of cases per 100,000 people in the population) show signs of decline or slower growth only among older cohorts, i.e., people who were in their thirties at the beginning of the epidemic. Incidence rates have not shown similar slowdowns among the younger cohorts, and there has been an especially acute increase in incidence for young injection drug users[28].

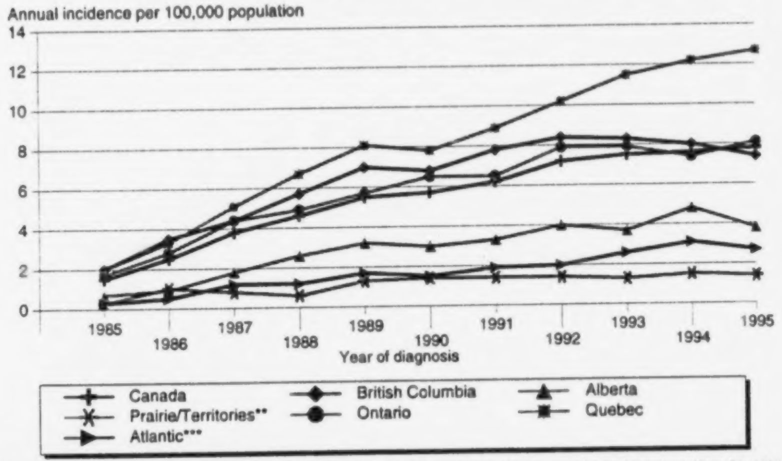
(d) Incidence by Region

In Exhibit 2.8, the total number of new AIDS cases in each region of Canada each year has been adjusted for the population of each region, to give annual incidence rates per 100,000 people. This figure shows that, taking the size of the

[28] LCDC, AIDS in Canada, 1996, Figures 6,7, and 8, pp. 22-23.

population of each region into account, Québec has the highest annual incidence rates, having climbed from 2.0 to 12.7 per 100,000 population from 1985 to 1995. Annual incidence rates in Ontario have grown from 1.7 per 100,000 population in 1985 to a high of 8.1 per 100,000 population in 1995, with a dip in 1994. In British Columbia, annual incidence seems to have peaked in 1992, at 8.4 cases per 100,00 population, and since then stabilized or declined. The other regions show either stable incidences or small increases, but the number of cases makes these hard to distinguish from random fluctuations. For example, the annual incidence per 100,000 population in 1995 is 1.4 in the Prairies and Territories, and 2.7 in the Atlantic provinces.

EXHIBIT 2.8
Annual Incidence of AIDS* Per 100,000 Population
By Region and Year of Diagnosis, Canada, Cases Diagnosed to December 31, 1995



* The incidences presented here were calculated by dividing the number of cases adjusted for the delay in reporting by the total population for each region for each year of diagnosis. If it is assumed that the characteristics of the population influencing AIDS are distributed differently in the regions, then comparisons should not be made between the incidences. In conclusion, these incidences are not standardized for comparison purposes.
** Includes Saskatchewan, Manitoba, Yukon, and Northwest Territories.
*** Includes Newfoundland, Prince Edward Island, Nova Scotia, and New Brunswick.
Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada*. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

Note that because HIV/AIDS is not distributed evenly in the general population, it would be misleading to compare the different regions directly. The proportion of each regional population in each exposure category may differ across regions, and the overall annual incidence cannot take this into account. For example, the injection drug using population may be proportionately larger in one province than another (because of factors such as the availability of drugs, differences in policing, general economic conditions, etc.), so the difference between regions will reflect differences between the populations rather than differences in the region's response to the epidemic. Also, people in some risk categories may migrate to larger urban centres for better access to elements of their preferred lifestyle, greater anonymity or other reasons.

(e) Comparison of AIDS Incidence with Other Countries

In Exhibits 2.9 and 2.10, we look at how the number and proportion of the population of AIDS cases in Canada compares to that of the other countries used in the international comparative case studies. The cumulative incidence of AIDS (total number of cases reported to date per 100,000 population) in the United States is four times higher than that of Canada. However, in Australia, the incidence rate is somewhat lower, at 2.9 per 100,000 population[29]. These cumulative AIDS incidence rates to July 1996 show Canada to be a country with a moderate level of infection.

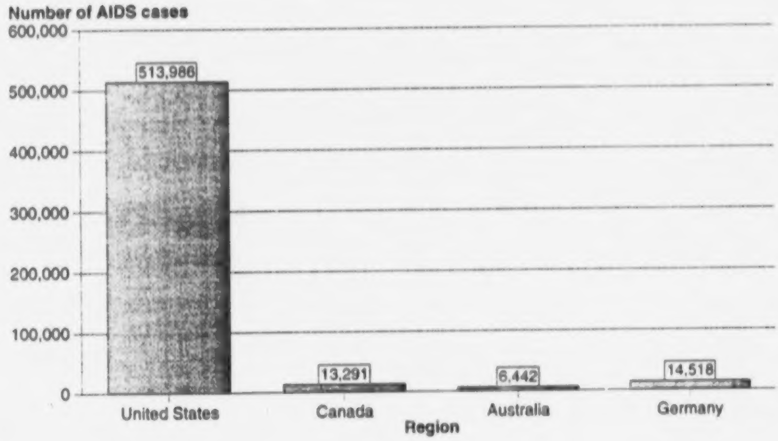
2.3 AIDS-Related Mortality

To date, a total of 10,837 deaths has been reported among Canadian AIDS cases. As throughout the early 1980's death followed AIDS diagnosis in one to five years, the pattern of AIDS deaths over the late 1980's and early 1990's closely follows the pattern of diagnoses several years previously. A 20 to 30 per cent decline in deaths attributed to AIDS has recently been reported. This decline probably reflects better care and treatment, but may also reflect underreporting[30].

[29] LCDC, AIDS in Canada, 1996, Appendix I.

[30] Health Canada, LCDC, Epi Update, May 1997.

EXHIBIT 2.9
Cumulative AIDS Cases in Different Countries, to July 1, 1996



Source: Health Canada, *AIDS in Canada: Annual report on AIDS in Canada.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB, Health Canada, 1996.

EXHIBIT 2.10
Cumulative AIDS Incidence Rate (per 100,000 population), 1995 Selected Countries

	Incidence Rate
United States	15.2
Canada	**3.4**
Australia	2.9
Germany	1.5

Source: Health Canada, LCDC, Annual Report on AIDS in Canada, December 1996, Appendix I.

(a) Mortality from AIDS and Other Causes

Because reliable data are available for mortality from other causes in Canada during our period of interest, it is possible to compare AIDS-related mortality to other leading causes of death.

As Exhibit 2.11 shows, between 1987 and 1992 there were 5,446 deaths attributed to HIV/AIDS. In the same period, there were 48,195 deaths from coronary heart disease, 19,398 from road accidents, 18,647 from suicide, 19,521 from lung cancer and 12,414 from breast cancer. One way of examining the impact of these deaths on Canadian society is to calculate how long each person who died would likely have lived (life expectancy) and then calculate how many years were lost because of the deaths. The potential years of life lost from HIV/AIDS for men is fourth after motor vehicle accidents, suicide and heart disease[31]. This shows that while AIDS affects relatively few individuals compared to other causes of death, because it affects mainly younger people, it results in more potential years of life lost.

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[31] Hogg, R., Heath, R., Strathdee, S., Montaner, J., O'Shaughnessy, M., Schechter, M. (1996) HIV/AIDS mortality in Canada: Evidence of gender, regional and local differentials. AIDS, 10(8), 889-894.

EXHIBIT 2.11
Mortality Ratios (deaths per 100,000 age-adjusted population) for Certain Causes of Death, Canada, 1987-1992

Cause of death	Observed deaths	ASMR[1] 25-44 years
Men		
Heart disease	37,964	13.2
Lung cancer	19,521	3.6
Suicides	14,691	28.4
Motor vehicle accidents	14,004	21.5
HIV/AIDS	5,156	14.4
Women		
Heart disease	10,231	2.3
Breast cancer	12,414	9.5
Motor vehicle accidents	5,390	7.3
Suicides	3,956	7.8
HIV/AIDS	290	0.7

Source: Hogg, R., Heath, R., Strathdee, Montaner, J., O'Shaughnessy, M., Schechter, M. (1996).

[1] Age standardized mortality ratio: the rate of mortality taking into account the age structure of the population.

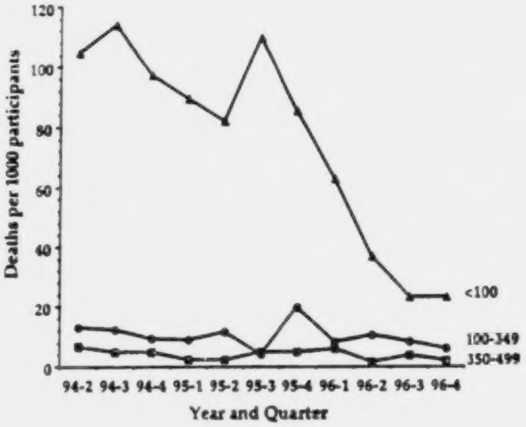
(b) Changes in Mortality for Those in Treatment

Exhibit 2.12 shows another way of looking at AIDS-related mortality in relation to the effects of NAS-II. One component of NAS-II, support to the Clinical Trials Network, was devoted to developing effective treatments for AIDS-related illness. In a study of death rates for individuals on antiretroviral treatment, one of the main research focuses of the clinical trials, the quarterly rate of death decreased steadily between January 1994 to November 1996. Benefits were greatest for the sickest individuals, i.e., those whose immune systems were functioning least well[32]. To the extent that these improvements in survival for these trial participants can be associated with efforts that were part of NAS-II, they suggest an effect of the Strategy on those participants. To affect the epidemic as a whole, the treatments would have to become available and used for a large proportion of appropriate cases. Other research is ongoing on long-term survivors and non-progressors to AIDS.

EXHIBIT 2.12

Death Rates for Participants on Antiretroviral Therapy in the HIV/AIDS Drug Treatment Program

British Columbia Centre for Excellence in HIV/AIDS, by CD4 Cell Count, (April 1994 to November 1996)



Source: Status Report, November 1996, The HIV/AIDS Drug Treatment Program, BC Centre for Excellence in HIV/AIDS.

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[32] Based on incomplete information in: Canadian HIV Trails Network: Background Information, January 28,1997; and British Columbia Centre for Excellence in HIV/AIDS, The Battle Isn't Over. Forecast: The Journal of the BC Centre for Excellence, March 1997.

(c) Summary: What This Tells Us About AIDS in Canada Over the Period of NAS-II

As stated above, these data on AIDS are best seen as providing a backdrop to understanding of trends in infections that occurred well before NAS-II and its predecessor, NAS-I, were introduced. These data, with the exception of mortality data, are only indirectly useful for assessing the effect of the Strategy on the epidemic.

Overall, the data show that NAS-II was introduced at a point when the original waves of the epidemic were beginning to subside. HIV transmission five to ten years before NAS-II, in 1983 to 1988, had declined so that by the time NAS-II was introduced, AIDS cases had begun to decline. The Strategy's timing in this sense was propitious, but it could not have been responsible for the observed declines. Second, because the number of cases among men who have sex with men was very high (80 per cent of all cases), the overall evolution of the epidemic followed the evolution in this group. However, this may have dwarfed other problem areas: increasing incidence in youth, injection drug users, aboriginal people, and women. The following chapter, focusing on HIV, will examine what effects NAS-II might have had in all these groups.

CHAPTER

3 HIV IN CANADA 1985 TO 1996 IN RELATION TO NAS-II

In this chapter, we present a cumulative portrait of HIV infection in Canada, by main risk group and region. Because NAS-II could plausibly have affected transmission of HIV beginning in 1993 (and NAS-I in 1990), we will pay particular attention to those periods. Positive HIV test reports from voluntary testing are reported independently by each province to Health Canada's National HIV Database Project, without personal identifiers but with risk factor information when it is known. No information is available on those whose test is negative.

3.1 Number of HIV Infections: Total Burden of HIV on Canadians

From 1985 to 1994, 33,520 positive HIV tests were recorded in Canada. In 1995, another 3,093 cases were found. It is now estimated that the total number of HIV-positive individuals, including the almost 15,000 with AIDS, is between 36,000 and 42,000 people. An estimated 50,000 to 54,000 people have ever been infected with HIV in Canada. About 3,000 to 5,000 new infections occurred in 1996, up from the estimated 2,500 to 3,000 per year in 1989-94[33]. This wider range in the 1996 estimate represents increased difficulty in making these estimates due to changes in the natural history of the epidemic: the methods used to estimate HIV infection must now be adapted to new populations and to account for effects of new treatments.

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[33] Health Canada, LCDC, Epi Update, May 1997.

(a) Positive HIV Tests by Exposure Category and Sex

Exhibits 3.1a and b shows the cumulative number of positive HIV test reports by exposure category and sex for the period from 1985 to 1994. Males accounted for 28,542 or 85 per cent of all positive tests, again showing the predominance of the epidemic among men in Canada.

EXHIBIT 3.1a
Cumulative 10-Year (November 1, 1985 to December 31, 1994)
HIV Positive Test Reports in Canada,
Exposure Category by Sex

Exposure Category	Male	Female	Unknown	Total	Percent
MSM	12,095	14[1]	113[1]	12,222	36.5
MSM/IDU	321	3[1]	2[1]	326	1.0
IDU	1,093	330	35	1,458	4.3
Heterosexual contact/endemic	629	451	22	1,102	3.3
Blood/blood products	565	152	31	748	2.2
Perinatal	76	54	4	134	0.4
Other	480	169	25	674	2.0
Unknown/NIR	13,283	2,004	1,569	16,856	50.3
Total	28,542	3,177	1,801	33,520	100.0

1. Due to provincial/territorial differences in exposure categories, some cases may be misclassified. Data will be revised on an ongoing basis.

Source: Health Canada, *HIV in Canada: Surveillance report for the period 1985-1995.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, Health Canada, 1996.

EXHIBIT 3.1b
1995 (January 1, 1995 to December 31, 1995)
HIV Positive Test Reports in Canada, Exposure Category by Sex

Exposure Category	Male	Female	Unknown	Total	Percent
MSM	820	0	2[1]	822	26.6
MSM/IDU	68	4[1]	2[1]	74	2.4
IDU	293	117	6	416	13.4
Heterosexual contact/endemic	159	113	2	274	8.9
Blood/blood products	27	14	0	41	1.3
Perinatal	14	31	2	47	1.5
Other	36	44	2	82	2.7
Unknown/NIR	1,000	262	75	1,337	43.2
Total	2,417	585	91	3,093	100.0

1. Due to provincial/territorial differences in exposure categories, some cases may be misclassified. Data will be revised on an ongoing basis.

Source: Health Canada, *HIV in Canada: Surveillance report for the period 1985-1995.* Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, Health Canada, 1996.

For half of the positive HIV tests from 1985 to 1994, no known risk factor was available. Men who have sex with men (excluding those who are also injection drug users) accounted for 37 per cent of positive tests, or almost three-quarters of positive tests among those with at least one known risk factor. In contrast, in 1995, this category accounted for 27 per cent of positive tests or 47 per cent of positive tests among those with at least one known risk factor. In 1995, the two injection drug use categories (including injection drug users who are also men who have sex with men) were associated with 5.3 per cent of all positive tests where at least one risk factor was known. Finally, 10 per cent of positive tests taken between 1985 and 1994 were taken by women, whereas in 1995, 19 per cent of positive tests were taken by women.

On the surface, these data could suggest a positive effect for government intervention in HIV/AIDS among men who have sex with men, and a lack of effect for injection drug users and women. However, this is only one possible explanation for these effects, and the following cautions are necessary.

First, due to differences in the successful removal of duplicates, data from 1995 and the 1985-1994 period are not strictly comparable. Also, the one-year period in 1995 may reflect normal statistical variation that has not been evened out.

Second, as the data on AIDS in the previous chapter shows, there seemed to be a decline in the epidemic among men who have sex with men prior to NAS-II. The Strategy may have accelerated that decline but it could not have initiated it. Moreover, the absolute number of infections remains a critical factor for interpretation of the evolution of HIV infections: despite the *relative* decline, by far the greatest *number* of positive tests in 1995 (822 out of 3,093) were among men who have sex with men.

Regarding injection drug users and women, the data in the previous chapter also show a steady increase in diagnoses in these groups prior to the Strategy. Although NAS-II may have had no effect on transmission in this group, it also could have slowed the increase.

Finally, it must be noted that because there is no known risk factor for half the cases, the proportions in each exposure group could be very biased. It would be unreasonable to assume that the distribution of risk factors in the missing 50 per cent of cases will be identical to that in the 50 per cent of cases where this information is available. More likely, certain risk groups are underrepresented in the missing cases — perhaps those whose risk behaviours carry a moral stigma, or are less visible or salient.

(b) Positive HIV Tests by Exposure Category and Age

Exhibits 3.2a and 3.2b show how old HIV positive individuals were when they had their first known positive HIV test. From 1985 to 1994, positive tests were most frequently found among those aged 30 to 39 (37 per cent), followed by those aged 20-29 (28 per cent). In 1995, 44 per cent of positive tests were in people aged 30 to 39, while 24 per cent were in people aged 20 to 29. While this may suggest that the average age of first known HIV test has increased over the last decade, without information on all those tested, with positive or negative results, this remains a hypothesis. The already relatively small number of positive tests among those aged 15 to 19 declined from 1.4 per cent of all positive tests in 1985 to 1994 to 0.9 per cent of positive tests in 1995. This is out of step with the data on AIDS incidence, which show steady increases in AIDS diagnoses in cohorts aged 19 or under at the onset of the epidemic. Because the latest gains in treatment appear to help most those who are diagnosed earliest, it would seem desirable that testing and thus the number of positive tests found be on the increase among younger people.

(c) Positive HIV Tests by Region

Like AIDS, HIV infection testing is distributed unevenly across Canada. In 1995, Ontario, Québec and British Columbia accounted for 90 per cent of positive tests. There is likely some underrepresentation in provinces where testing is less accessible. Some people may also travel to larger urban centres, perhaps outside of their province, to be tested.

EXHIBIT 3.2a
Cumulative 10-Year (November 1, 1985 to December 31, 1994) HIV Positive Test Reports in Canada, Province/Territory by Age Group

	Age Group at Time of First Known HIV Positive Test							
Province/Territory	**<15**	**15-19**	**20-29**	**30-39**	**40-49**	**>50**	**Un-known**	**Total**
British Columbia	100	123	2,359	3,224	1,437	522	366	8,131
Alberta	26[1]	44[1]	622	676	294	108	632	2,402
Prairies/Territories	16	19	261	247	77	41	130	791
Ontario	236	174	3,984	5,308	2,461	883	2,210	15,256
Quebec	37	90	1,770	2,648	1,110	464	53	6,172[2]
Atlantic Provinces	20	31	263	267	114	38	35	768
Total	**435**	**481**	**9,259**	**12,370**	**5,493**	**2,056**	**3,426**	**33,520**
Percent	**1.3**	**1.4**	**27.6**	**36.9**	**16.4**	**6.1**	**10.2**	**—**

[1] For Alberta data in this report, cases in the 0-9 age group category were reassigned to the < 15 category and those in the 10-19 age group category were reassigned to the 15-19 category.

[2] Quebec data are based on the minimum number of HIV positive individuals with duplicates removed. The number of positive tests for Quebec is higher but for the majority of the remaining test reports duplicates could not be ruled out.

Source: Health Canada, *HIV in Canada: Surveillance report for the period 1985-1995*. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, Health Canada, 1996.

(d) Incidence Studies

An inventory of a total of 88 studies of HIV incidence and prevalence in specific samples is regularly compiled by LCDC[34]. These include studies where data is collected in sentinel hospitals, sexually transmitted disease (STD) clinics, physicians' offices, outreach clinics, needle exchanges, prisons and blood donor clinics. These studies suggest that new infections are becoming less common among men who have sex with men, especially the older members of this group[35]. The most recent data suggest that at the same time, incidence appears to be increasing among injection drug users, especially in Vancouver[36].

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[34] Health Canada, LCDC, Inventory of HIV Incidence and Prevalence Studies in Canada, May 1997.

EXHIBIT 3.2b
1995 (January 1, 1995 to December 31, 1995) HIV Positive Test Reports in Canada, Province/Territory by Age Group

	Age Group at Time of First Known HIV Positive Test							
Province/Territory	**<15**	**15-19**	**20-29**	**30-39**	**40-49**	**>50**	**Un-known**	**Total**
British Columbia	4	4	190	299	141	42	8	688
Alberta	13[1]	5[1]	44	73	29	14	4	182
Prairies/Territories	1	2	31	31	10	3	0	78
Ontario	41	8	292	606	258	125	54	1,384
Quebec	6	8	164	311	158	54	0	701[2]
Atlantic Provinces	0	2	12	26	11	4	5	60
Total	**65**	**29**	**733**	**1,346**	**607**	**242**	**71**	**3,093**
Percent	**2.1**	**0.9**	**23.7**	**43.5**	**19.6**	**7.8**	**2.3**	**—**

[1] For Alberta data in this report, cases in the 0-9 age group category were reassigned to the < 15 category and those in the 10-19 age group category were reassigned to the 15-19 category.

[2] Quebec data are based on the minimum number of HIV positive individuals with duplicates removed. The number of positive tests for Quebec is higher but for the majority of the remaining test reports duplicates could not be ruled out.

Source: Health Canada, *HIV in Canada: Surveillance report for the period 1985-1995*. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, Health Canada, 1996.

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35. For example, Vancouver Lymphadenopathy AIDS Study, cited in Health Canada, Inventory of HIV Incidence and Prevalence Studies in Canada, May 1997.

36. Patrick, D., Strathdee, S., Currie, S., et al. (1997) HIV Incidence in the Vancouver IDU Study Cohort. Abstract no. 219, Canadian Association of HIV Research Conference, Ottawa.

3.2 Summary: What this Tells Us About HIV in Canada Over the Period of NAS-II

These data suggest that rates of HIV transmission in Canada are changing, probably in response to a number of factors one of which may be government supported intervention. Although rates of infection among the older cohorts of men who have sex with men may be stabilizing, they may be increasing among younger cohorts in this group, among injection drug users, among aboriginal people and women.

CHAPTER

4 SUMMARY AND CONCLUSION

As stated in Chapter 1, this chapter acknowledges that data are never neutral but rather are always proposed and interpreted within a particular set of values and interests. In the following pages, we make some summary statements about the evolution of the HIV/AIDS epidemic in Canada, while proposing alternative interpretations of each. These alternative interpretations are intended to frame the examination of NAS-II's actual action and impacts in the evaluation proper.

4.1 Summary Statement 1: Overall Epidemic and Burden on Canada

Overall, the data suggest that the rate of increase (i.e., the spread) of the epidemic has slowed and may be stabilizing. This may suggest that effective mobilization and intervention have been achieved — notably among the most affected target group, men who have sex with men — and that public resources may be more cost-effectively used to tackle other population health problems. Alternatively, the data may be luring us into a false sense of complacency because the overwhelming influence of the exposure category "men who have sex with men" obscures potential increases among injection drug users, among youth, among aboriginal people, among women and therefore among children.

4.2 Summary Statement 2: The Public Health Threat

While in many countries heterosexual transmission in the general population, fed through heterosexual transmission in core groups, is the principal route of HIV spread[37], the portrait of HIV/AIDS in Canada was and remains characterized by specific subpopulations, notably among men who have sex with men.

This may mean that public health threat, that is the danger of heterosexual transmission of HIV/AIDS in the general Canadian population, remains minimal, insofar as the community of men who have sex with men has been mobilized to pursue prevention goals. Alternatively, the continued high number of new infections among homosexual and bisexual men, the growth in infection among IDU's, youth, aboriginal people and women all suggest that continued vigilance and effort are necessary, especially in Canada's largest cities.

4.3 Summary Statement 3: Potential Effects of NAS-II on the Epidemic

The main objective of this paper was to describe the epidemic during the period when the National AIDS Strategy could have affected it. Given the current data, it is very difficult to speculate about when and among whom those effects could have been observed. Over the period covered by NAS-II, positive changes were seen in the exposure category "men who have sex with men". These changes were likely underway before NAS-II was introduced. However, even though the positive changes observed among men who have sex with men may have begun prior to and independently of NAS-II, the Strategy may have enhanced or accelerated those changes. If a momentum for gaining on the epidemic had been started in this group before NAS-II, the Strategy may have been able to boost and maintain the effects of this momentum over a threshold level of intervention. Over the same period, there were increases in infection among youth, injection drug users, aboriginal people, and women. These changes may also have been underway before NAS-II, but the Strategy may have slowed their growth.

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[37] United Kingdom Overseas Development Administration, Communicable Disease Surveillance Centre (1996). Sexual Health and Health Care: HIV, AIDS and Sexually Transmitted Infections. Global Epidemiology, Impact and Prevention. London: ODA.

4.4 Conclusion

The true effects of the National AIDS Strategy on the evolution of HIV/AIDS in Canada may not be clearly visible until five to 10 years from now. During the period NAS-II has been in place, progress seems to have been made in two areas: lower rates of transmission of HIV among men who have sex with men, and in fewer deaths due to AIDS. During the same period, infection rates have increased among youth, injection drug users, aboriginal people, and women. Because the incidence of new HIV infections has increased since the early 1990's, the burden of HIV illness on Canadians cannot be said to be declining.

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 4:
Provincial Activities in HIV/AIDS

September 2, 1997

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 4: Provincial Activities in HIV/AIDS

1. Description of Provincial Activity in HIV/AIDS[1]

(a) Newfoundland

In December 1993, three working groups — Prevention and education; Testing and Treatment; and Care and Home Support — submitted recommendations to the Minister of Health. Twenty-three recommendations were written in a document entitled *Towards the Development of a Comprehensive HIV/AIDS Strategy for Newfoundland and Labrador*. All recommendations were adopted by the Department. Yearly reviews through stakeholder consultations have been held since 1994 to assess outcomes in light of these recommendations. The next review is scheduled for fall 1997. This year's review will include consultations on the next national strategy (if such is the case) to see for example what new collaboration and intervention models could be developed through the next NAS.

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[1] Note: information was not obtained from all provinces and territories, hence this technical report presents the activities for only ten provinces.

(b) New Brunswick

New Brunswick does not have anything structured (e.g., strategy, committee, etc.) on the topic of HIV/AIDS. The number of cases in the province is low and this area is not a main priority. The province does, however, have a number of activities in place. These include the funding of insured services under Medicare, financial coverage of certain drugs, the funding of an HIV/AIDS information line (run under contract by AIDS New Brunswick), and peer programs for homosexuals and people who are HIV positive. Other activities are handles at the regional public health level, and vary by region.

(c) Prince Edward Island

Prince Edward Island designed a provincial HIV/AIDS Strategy that has two goals: 1) a prevention and education goal to prevent everyone on PEI from contracting HIV; and 2) a care, treatment and support goal to provide accessible care, treatment and support services to those infected/affected by HIV/AIDS. The purpose of the strategy is "to allow for community groups, people living with HIV/AIDS and government representatives to share strengths in a sustained effort to deal with the disease on Prince Edward Island". The Strategy established partnerships between the Departments of Education and Health and Social Services, the Health and Community Services system, AIDS PEI, the Hemophilia Society and persons infected/affected with HIV/AIDS.

(d) Nova Scotia

The Nova Scotia Advisory Commission on AIDS was appointed in 1989. It includes a Chairperson, two members and two staff members. The Commission produces recommendations for the provincial Minister of Health and maintains information and library services.

(e) Quebec

Quebec's strategy for combatting AIDS and preventing sexually transmitted diseases was first implemented in 1987. Its annual budget for 1997/98 is $19M. It aims at: 1) preventing STDs and HIV infection; 2) improving the quality of care and services available to HIV and AIDS sufferers; and 3) promoting non-discrimination and compassion towards victims. The Centre québécois de coordination sur le SIDA (CQCS) is mandated by the Quebec Ministry of Health and Community Services to advise the Minister on AIDS and to coordinate action plans in seven areas: education and prevention; communications; training; epidemiological monitoring; development of service and care programs; links to and funding of community-based groups; and research and evaluation. Regarding prevention and education, the CQCS supported activities targeted at: youth; drug users; men who have sex with men; women; ethnic groups; Aboriginal groups; the homeless; prisoners and health professionals. The CQCS also collaborates with NGOs and health professionals to meet demands in housing and home assistance services for people living with AIDS.

(f) Ontario

The province of Ontario spends approximately $40M a year on HIV/AIDS related programs and services. In 1992, the Ontario Advisory Committee on HIV/AIDS, at the request of the Minister of Health, undertook the development of a comprehensive plan to guide all HIV/AIDS activities in the province. *Building on Our Strengths: Focusing Our Efforts* is a two-part strategy for planning Ontario's HIV/AIDS activities until the year 2000. The goal of this strategy is to prevent the further spread of HIV infection and to improve the quality of life for people living with HIV/AIDS by maintaining and refining the current infrastructure according to its strengths and by focusing on programs and activities that have the greatest potential for impact, as well as on the areas of greatest need. As needs will change, resulting in changes in priorities, the plan will be updated regularly. Programs and services currently provided include: outpatient clinics; a provincial drug distribution system, needle and syringe exchange programs; sites designated to offer anonymous HIV testing, Public Health HIV/AIDS programs; and provincially funded community-based HIV/AIDS groups or programs.

(g) Manitoba

The province of Manitoba implemented an AIDS Strategy in July 1997. Its goal is to reduce the spread of HIV infection, provide a continuum of compassionate prevention, care, treatment and support programs for persons at risk of and/or living with HIV/AIDS, and to facilitate the planning, delivery and evaluation of all programs/efforts. The provincial AIDS Committee determines how priorities should be addressed and by whom. Special talks are also carried out by special multi-disciplinary working groups.

(h) Saskatchewan

Saskatchewan released Phase One of an AIDS Strategy in 1993. This strategy included commitment to institute anonymous testing in the province; provided a policy on reporting of AIDS cases, disclosure guidelines and partner notification; and a commitment for community action and to provide palliative care. This Strategy was implemented. As a result, for example, Saskatchewan now offers anonymous testing and needle exchange programs in three locations. A number of activities have occurred since the completion of this strategy. Additional provincial activities have included the provision of financial support to Aboriginal groups, collaboration with the Department of Education to establish HIV/AIDS curriculum to be implemented at the primary school level this fall, and working with Corrections to provide easy access to condoms etc..

(i) Alberta

In 1987, the Government of Alberta established a Provincial AIDS Program that identified strategies in prevention and control, education of workers, epidemiological surveillance and assessment, laboratory diagnosis and screening, care and treatment programs, and research initiatives. The program has provided community funding, resources to schools, workshops and resources for health authorities, presentations for health professionals, counselling, a toll-free information line, a health library, campaigns, and coordination of HIV testing through provincial labs.

(j) British Columbia

British Columbia has implemented a wide range of activities on the subject of HIV/AIDS. In 1995, the B.C. government allocated more that $7 million for community-based AIDS education and prevention programs. Provincial programs cover the full spectrum, with activities divided into four categories: health maintenance and enhancement, risk avoidance, risk reduction, early intervention, and treatment and support. Health enhancement activities and services include public awareness activities and educational material, a resource library, school-based prevention workers and the B.C. Native AIDS Awareness Program. Risk avoidance activities also include education activities targeting at-risk populations, Street Outreach, Prison Outreach, and condom distribution. Risk reduction activities include needle exchange services, STD clinics, prenatal and immigration/refugee testing, methadone maintenance and Corrections programming in jails. Early Intervention activities include information dissemination (treatment information and helpline), support and care services, frontline counselling services, and research (including medication/treatment trials). Finally, treatment and support activities include information dissemination, advocacy, services (including counselling, support groups, case management, referrals, home outreach, medical equipment, housing, transportation, emergency assistance, etc.), physician care, hospital and home nursing care, hospice, etc.

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 5:
International Comparative Case Studies

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TABLE OF CONTENTS

EXECUTIVE SUMMARY vi

1 INTRODUCTION 1

- 1.1 Purpose 1
- 1.2 Choice and Comparability of Comparison Countries 2
- 1.3 Definition of National AIDS Programs 3
- 1.4 Dimensions of Comparison 4
- 1.5 Limits of this Approach 5

2 COMPARATIVE ANALYSIS 7

- 2.1 Epidemiology of HIV/AIDS 7
- 2.2 Background to the Programs 10
- 2.3 Level of Commitment 15
- 2.4 Relationship Between Governmental and Non-governmental Sectors 19
- 2.5 Program Management 23
- 2.6 Response in Prevention 27
- 2.7 Response in Care and Treatment 30
- 2.8 Research 33
- 2.9 Sustainability 35
- 2.10 Evaluation 38

3 DISCUSSION AND CONCLUSION 41

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 5: International Comparative Case Studies

EXECUTIVE SUMMARY

An evaluation of the continued relevance, success and cost-effectiveness of Canada's National AIDS Strategy, Phase II was planned for 1997. As part of this evaluation, Canada's national HIV/AIDS program was compared to those in three other countries. This document presents the results of the comparisons, focusing on alternative national responses to the epidemic, including program leadership, organization, funding and focus, as well as an estimate of relative effectiveness. The purpose of this comparative analysis is to help assess the overall adequacy of NAS-II in response to AIDS in Canada, by examining how other countries grappling with similar problems have faced the epidemic. It is hoped that this information will be useful to the consideration of alternatives for the National AIDS Strategy, Phase III.

Canada's response in comparison to other countr

The choice of comparison countries was made so as to illustrate national approaches to the HIV/AIDS epidemic in industrialized countries which share certain characteristics with Canada. First, it was considered important to compare Canada's response to that in countries with ① a similar epidemic, i.e., with the same ② main risk groups and modes of transmission. Second, so that the amount of collective resources available to the central government would be comparable, consideration was given to selecting countries which were similar to Canada in terms of major social and economic indicators such as GDP per capita. Although the three countries used — the United States, Australia and Germany — represent rather different populations, economies, cultures and governmental structures, they are similar enough to Canada in these respects to permit useful comparisons. The perceived success of their national * programs was not a factor in the choice of countries.

Epidemiology of HIV/AIDS

gay men
blood product
recipients
other
IDU's

Epi - cause or backdrop - rather than effect.

The epidemiological situation in the four countries is best viewed as cause or backdrop to, rather than effect, of their response to the epidemic. Overall, the pattern of spread of HIV infection in the four countries is similar: the first cases appeared in the early 1980's; early waves of the epidemic were among men who have sex with men and recipients of blood products; and later waves were among injection drug users with increases in heterosexual transmission. Based on the data available from those countries which collect it, HIV/AIDS is increasingly a phenomenon of minority and marginalized populations, already difficult to reach through public health measures.

Canada - middle of road.

?? The HIV/AIDS epidemic in Canada can be characterized as moderately strong. While much less of a problem than in the United States, HIV/AIDS in Canada is a greater problem than in many other industrialized countries, including Germany and Australia.

Background to the Programs

national responses shaped by countries existing health care system.

In industrialized counties, national programs to combat HIV/AIDS began to be implemented in the early 1980's, with a peak number being created in 1987 or shortly after the 1987 WHO World Health Assembly. In most of these countries, a small set of common factors provided political impetus for their programs, although their relative influence varied from country to country. Chief among these factors were: 1) awareness of cases infected through the blood supply, and in many cases, concern over negligent or slow government response; 2) mobilization of community groups, particularly among gay men; 3) deaths of prominent people; and 4) awareness of cases infected through contact with health workers. The relative strength of each of these factors, especially the extent to which the gay movement was organized before the onset of the epidemic, have shaped each country's response to it. Each country's program has also been shaped by the structure of its existing health care system. In the four cases studied here, only the United States does not have a nationalized health system.

→ in what sense??

with international component

These four national programs are quite similar ~~in~~ many respects. All contain the same basic objectives: to prevent (1) new infections, to care (2) for those infected, to produce research (3) breakthroughs for both of these. All also included an international component. However, emphasis on civil rights and on social acceptance of people with HIV or AIDS varies from country. In Canada, this is not an explicit focus at the level of the overall program objectives, although present in program activities. Canada's program is also the only one of the four studied to include an objective of implementing the strategy effectively.

Level of Commitment

- financial
- political

Level of federal government commitment to the HIV/AIDS Strategy is examined in two ways: in terms of financial support to the strategy, and in terms of political commitment.

It is difficult to compare the level of federal commitment to AIDS programming in these countries, mainly because of their differences in terms of responsibility for management and delivery of health care and presence of nationalized health systems. However, they all have tried to balance allocations among prevention, care and treatment, and research. Degree of federal political commitment and responsiveness to HIV/AIDS has varied more significantly, with both Australia and Germany showing an earlier mobilization of federal commitment (in terms of both funding and release of a national program) than Canada, and with the United States lagging far behind.

① Australia's Germany first with national program
② followed by Canada
③ US far behind.

Relationship Between Governmental and Non-governmental Sectors

Analysts of national AIDS programs agree that good interministerial collaboration, over and above the involvement of the health ministry, and strong participation of the non-government sector are necessary for effective national programs. Several reasons are given for this: NGO's may be more cost-effective (or simply less costly) than public services, may be more responsive to emerging needs, may be able to more effectively represent needs and values of particular groups, and have better access to target communities, especially among marginalized groups. The involvement of multiple agencies may increase diversity in program interventions, and second, may create broader and more sustainable support in the population. In a survey of 14 national programs conducted in 1992, about 15 per cent of program funds (with a range of from five per cent to 50 per cent) were allocated to NGO's.

critical role of collaboration & the important role of NGOs

→ sustainability

Federal programs in three of these four countries — Germany, Australia and Canada — have developed close relationships with the non-government sector, as a function of a strong partnership orientation in their strategies. Support for both umbrella local organizations is provided, but with other levels of government (provincial or state, regional, or municipal), also providing support to local organizations. In all cases, including the United States, these relationships have provided additional range and flexibility of intervention, sometimes allowing controversial programs to be implemented not directly by government, but with its indirect support (e.g., needle exchange programs). These relationships with the non-governmental sector, notably with gay advocacy organizations, have also allowed federal governments to demonstrate leadership in the human rights issues associated with HIV/AIDS. On the negative side, these partnerships have, in all countries studied, sometimes caused frictions between the more conservative bureaucracies and the more audacious non-government groups.

Program Management

difference between responsibility

In many countries, national responsibility for HIV/AIDS is located within the national health ministry, although in some cases responsibility is shared with another ministry (e.g., education), and in others a new national agency was created. Federal states (i.e., composed of provinces or states with their own levels of government) have generally adapted existing coordination and communication mechanisms between levels of government, in a multi-layered approach. Coordination and communication problems due to these layers are noted in many industrialized countries. A global tendency toward decentralization and horizontal integration is reported. Integration of STD and HIV/AIDS programs is regarded as a central issue in this tendency as are links to primary care and social services.

- gov't. .
- similar issues.
- horizontality.
- communication

The structures and reporting relationships of these federal AIDS strategies have all been determined by those existing for the health system in their respective countries. In Canada, Australia and Germany, health care delivery is a provincial or state responsibility but a federal entity provides policy, coordination and funding. The AIDS programs have been closely associated with this federal body, and have made use of existing mechanisms for federal-provincial coordination, notably conferences of health ministers. Of these three, Australia seems to have been the most successful, and Canada the least, at ensuring clear division of responsibility. In all countries, national advisory bodies with broad representation have been set up, and all have played major roles in the development of policy.

Response in Prevention

need for diverse strategies

According to analysts of national AIDS programs, adequate prevention response should include activities in information diffusion and awareness, education and preventive services. Moreover, it is generally believed the use of diverse strategies will be associated with greater effectiveness.

similar responses
difference is the investment.

With similar epidemics, these four countries have made similar responses in prevention, to roughly the same target groups. However, their relative contribution to prevention as opposed to other program goals seems to vary substantially (although these figures should be taken only as very broad estimates): Germany has made the greatest relative investment in prevention, the U.S. the smallest, with Canada and Australia lying in between.

Response in Care and Treatment

The adequacy of response in care and treatment, including medical and social services is next to be examined. Of particular interest here is how these countries have chosen to position HIV/AIDS care and treatment in the context of their existing health systems.

- CTS positioned within the existing system

All four countries have attempted to develop or reinforce health system infrastructures to ensure that people living with HIV/AIDS have access to comprehensive and high-quality care, treatment and support. In the United States, the combination of a lack of a nationalized health system and the concentration of the epidemic among those without private health insurance has created some barriers to access. In Germany and Australia, program funds have been delivered directly to existing health infrastructures in order to improve access to and quality of treatment and care. In Canada, this response has been much more indirect, as the federal strategy actually excludes federally-supported action on matters in provincial jurisdiction.

- develop infrastructure to ensure access & comprehensive care.

US - difficulties with private system
Ger. & Aust. - direct
Can - indirect.

Which approach is most effective?

Research

Commitment to research in federal programs has aimed to improve intervention at all levels, both within the research sponsor's country and by contributing to international research efforts.

All of the countries studied have allocated significant resources to HIV/AIDS research in the complete spectrum of research domains. Although the United States has made a larger absolute and per capita commitment to research, Canada's proportional investment in research is somewhat greater than that in other countries.

per capita investment.

Sustainability

The sustainability of national AIDS programs is a greater issue in developing countries, particularly in Africa, where the combination of limited collective wealth and a more stronger epidemic raise serious questions about central tendency to mainstream in Canada programs now in A-land.

- sustainability is not a question of lack of resources.

governments' capacities to continue to respond to the epidemic. Nevertheless, sustainability of national AIDS programs in industrialized countries is also of interest, because economic pressures and ideological differences regularly cause all such investments to be requestioned. Given the worldwide tendency of mainstreaming AIDS programs, sustainability may also come to be synonymous with degree of integration into existing health, social service, and research systems.

Because these nations are relatively wealthy, sustainability of a federal investment in HIV/AIDS programs is unlikely to be threatened by a lack of resources. Rather, sustainability is more likely to be a function of political choices, support from other levels of government, and long-term integration to existing health system structures. In this respect, Australia, and to some extent Germany, have been able to more explicitly delineate the boundaries of federal-provincial responsibility, and so have advanced farther into the sustainable integration of AIDS activities in the existing health and social services systems than have either Canada or the United States.

Evaluation

A survey of national AIDS programs conducted by the Global AIDS Policy Coalition revealed that only about half of programs in industrialized countries had been evaluated. In most cases, evaluation was conducted by national staff, with rare international participation.

All of the countries studied have made commitments to conducting evaluations of both progress and outcome. To date, Australia and Germany have produced evaluations of their national strategies, and Canada is in the process of doing so.

Discussion and Conclusion

These four national programs are quite similar in many respects. All contain the same basic objectives: to prevent new infections; to care for those infected; and to produce research breakthroughs for both of these. Responses in prevention have been similar, using a mix of educational and community development methods, often in partnership with community-based organizations growing out of gay community groups. Access to HIV testing, while not ideal everywhere, is generally without barriers. Responses ~~in care and~~ treatment have also been quite similar, aimed at providing a spectrum of adequate care while not excluding people from access to the best possible treatments.

In assessing the overall relative adequacy of the strategies, it seems that Canada is neither in the best nor the worst position, both the German and Australian programs present certain strengths in relation to the Canadian strategy. Both were introduced sooner than the Canadian strategy, and in the case of Australia, considerable advance planning had preceded the arrival of the epidemic. Australia, and to some extent Germany, have been able to more explicitly delineate the boundaries of federal-provincial responsibility, and so have advanced farther into the sustainable integration of AIDS activities in the existing health and social services systems. However, all three of the Canadian, German and Australian programs (but particularly the German), have been highly successful in working with community-based groups.

what lessons can Canada take away.

In terms of this comparative analysis, Canada's National AIDS Strategy-Phase II is distinguished positively by its relatively great investment in HIV/AIDS research and by its partnership approach.

↳ investment is great i partnership approach.

CHAPTER

1 INTRODUCTION

1.1 Purpose

In 1990, in response to the HIV/AIDS epidemic, the Canadian federal government implemented the National AIDS Strategy, Phase I. This was followed in 1993 by Phase II (NAS-II), funded from 1993 to 1998. A preliminary announcement has been made for a third phase of the Strategy.

An evaluation of the continued relevance, success and cost-effectiveness of Canada's National AIDS Strategy, Phase II was planned for 1997. As part of this evaluation, Canada's national HIV/AIDS program was compared to those in three other countries. This document presents the results of the comparisons, focusing on alternative national responses to the epidemic, including program leadership, organization, funding and focus, as well as an estimate of relative effectiveness. The purpose of this comparative analysis is to help assess the overall adequacy of NAS-II in response to AIDS in Canada, by examining how other countries grappling with similar problems have faced the epidemic. It is hoped that this information will be useful to the consideration of alternative forms for National AIDS Strategy, Phase III.

1.2 Choice and Comparability of Comparison Countries

The choice of comparison countries was made so as to illustrate national approaches to the HIV/AIDS epidemic in industrialized countries which share certain characteristics with Canada. First, it was considered important to compare Canada's response to that in countries with a similar epidemic, i.e., with the same main risk groups and modes of transmission. Second, so that the amount of collective resources available to the central government would be comparable, consideration was given to selecting countries which were similar to Canada in terms of major social and economic indicators such as GDP per capita. Although the three countries used the United States, Australia and Germany — represent rather different populations, economies, cultures and governmental structures, they are similar enough to Canada in these respects to permit useful comparisons. The perceived success of their national programs was not a factor in the choice of countries.

In addition, each of the three comparison countries also shares one or more important characteristics with Canada, for which it was important to examine alternative responses. The United States was chosen in part because of its cultural and geographical proximity, and in part because of our natural interest in comparing our actions to those of our influential neighbour. Of particular interest in Australia's national program is the response to the epidemic in the aboriginal population. While many other European countries would have provided interesting comparisons, the German federal-provincial system in some ways resembles the Canadian.

Despite the similarities between these countries and Canada, it will be important to keep their differences in mind and to take them into account in the comparative analysis. Table 1.1 presents some economic and social indicators for these countries, for 1991, a point at which Canada as well as the comparison countries were either planning or carrying out their federal HIV/AIDS strategy.

TABLE 1.1
Economic and Social Indicators Relevant to HIV/AIDS Programs
Canada and Comparison Countries, 1991

	Canada	United States	Australia	Germany
Population (M)	26.5	249.2	16.9	77.6
% Population Aged 15 to 64 yrs	67.9	66.1	66.9	69.5
% Population in Cities >500,000	62	77	68	45
GDP per capita ($US)	17,680	19,850	14,530	14,620
% central government expenditure on health	5.5	9.9	12.9	18.3
% GDP spent on health	8.6	11.2	7.1	8.2
Population per physician	510	470	440	380
Human Development Index	.983	.976	.973	.959

Sources: World Bank, *World Development Report 1991*; United Nations, *Human Development Report 1991*.

1.3 Definition of National AIDS Programs

National responses to HIV/AIDS vary widely throughout the world, so it is important to ensure that the analysis covers comparable elements in all the countries studied. In 1987, the WHO set forth criteria to define a national AIDS program, which included a National Advisory Committee, a focal point for program management, an intervention plan consistent with WHO global strategy, and a budget allocation. For purposes of this analysis, national AIDS programs are defined as:

> "the combination of collective actions that take place within the boundaries of a nation and have an overall plan, a management and coordination structure, a budget and a monitoring and evaluation capacity. These actions may involve governmental institutions and agencies, non-

governmental organizations, and the private sector" (Mann, Tarantola, & Netter, 1992, p.279).

1.4 Dimensions of Comparison

An analytic framework containing several dimensions of comparison was used to structure the comparative analysis. This framework was based on previous work by the Global AIDS Policy Coalition (Mann, Tarantola, & Netter, 1992) and the World Bank (Porter, 1996) identifying criteria to assess the quality, comprehensiveness and effectiveness of national AIDS programs. These dimensions are:

- ❑ level of political and financial commitment;
- ❑ degree of participation of and collaboration between governmental and non-governmental sectors;
- ❑ adequacy of program management, including mechanisms for program coordination, resource deployment and support, and use of existing structures and services;
- ❑ adequacy of response in prevention, including information, education and preventive services;
- ❑ adequacy of response in care and treatment, including medical and social services;
- ❑ level of research commitment;
- ❑ comprehensiveness of planning;
- ❑ sustainability and long-term perspective; and
- ❑ conduct and use of evaluation.

Each country's response will be described along each of the above dimensions.

1.5 Limits of this Approach

The validity of this comparative analysis will depend on the quality of the information available to it, i.e., on our ability to locate comparable, accurate and up-to-date information on programs in comparison countries. With limited resources for this component of the evaluation, only published material was used and no validation was conducted with representatives of the comparison countries. However, every effort has been made to use credible sources, either official program documents or peer-reviewed analyses. No attempt should be made to compare dollar values, as these have not been standardized to ensure that each represents spending on the same elements or activities. These have rather been included so as to provide a general picture of the countries' choices of relative level of investment.

CHAPTER

2 COMPARATIVE ANALYSIS

2.1 Epidemiology of HIV/AIDS

The epidemiological situation in the four countries is best viewed as cause or backdrop to, rather than effect, of their response to the epidemic. Overall, the pattern of spread of HIV infection in the four countries is similar: the first cases appeared in the early 1980's; early waves of the epidemic were among men who have sex with men and recipients of blood products; and later waves were among injection drug users with increases in heterosexual transmission. Based on the data available from those countries which collect it, HIV/AIDS is increasingly a phenomenon of minority and marginalized populations, already difficult to reach through public health measures.

(a) Canada

HIV/AIDS has been present in Canada since 1978, although systematic reporting was not established until 1982. As of April 15, 1997, 14,836 cases of AIDS and 10,837 deaths have been reported. In December 1996, the annual incidence of

AIDS in Canada was 3.4 cases per 100,000 population[1]. As of 1994, 33,320 positive HIV tests had been reported in Canada. It is currently estimated that roughly 39,000 people are infected with HIV in Canada.

As of 1995, 69.2 per cent of AIDS cases were among men who have sex with men, 14.5 per cent among injection drug users, and 16.6 per cent through heterosexual contact. Slightly less than two per cent (1.9 per cent) of all cases, were infected through the blood supply[2]. An increasing number of cases are being reported in the aboriginal population.

(b) United States

The first case of AIDS was reported in the U.S. in 1981, although the virus had been present for several years previously. As of February 1997, 573,800 cases of AIDS among people aged 13 or older had been reported. As of September 1996, 343,000 deaths due to AIDS had been reported. The annual incidence rate, of 15.2 per 100,000, is the highest among the industrialized countries[3]. It is estimated that in 1992 between 650,000 and 900,000 Americans were infected with HIV.

As in Canada, the early waves of the epidemic were among men who have sex with men. As of February 1997, 85 per cent of AIDS cases were male, but recent incidence trends show stabilization in this group. In September 1996, 32 per cent of cases were among injection drug users. The proportion of cases infected through heterosexual contact is increasing sharply. Fifty-three percent of AIDS cases are among nonwhites, mainly African-Americans and Hispanics. HIV infection is currently the leading cause of death among people aged 25 to 44.

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[1] Note that the most complete data on HIV/AIDS in Canada, with breakdowns by region and risk factors, were available only up to the end of December 1996 at the time of the evaluation. Wherever possible, the most recent summary data are used, but in some cases the December 1996 data are also used.

[2] Health Canada, 1996a. Total is more than 100% in source data.

[3] Note that the case definition for AIDS used in the United States is slightly different than that used elsewhere, resulting in more cases being counted as AIDS. Specifically, the European case definition for AIDS does not take into account the CD4 count criteria added by the CDC to their definition in 1993.

(c) Australia

AIDS was first reported in Australia in 1982-83. By the end of 1994, 5,737 cases of AIDS and 4,014 AIDS-related deaths had been reported in Australia. In 1995, the AIDS incidence rate was 2.9 per 100,000 population, among the lowest in OECD countries. The overall rate of increase in incidence is declining or has reached a plateau.

By the end of 1994, diagnosed cases of HIV infection totalled 18,725. Eighty-five percent of cases of diagnosed HIV infection have occurred in men who acquired it through homosexual contact. Injection drug users account for 5.7 per cent of all HIV infections to 1994, while heterosexual contact accounts for 5.2 per cent. A total of 432 people, or 2.6 per cent of cases, were infected with HIV through the blood supply[4]. An epidemic is believed to be emerging among aboriginal and Torres Strait Islander persons.

(d) Germany[5]

In Germany, the first cases of AIDS were reported in 1982. The cumulative number of cases, as of December 1996, was 15,682. With an annual incidence (in December 1995) of 1.5 per 100,000 population, Germany has one of the lowest rates in Europe. In 1992, it was estimated that between 50,000 and 60,000

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[4] Remaining cases include pediatric cases.

[5] See note 3.

Germans are infected with HIV. As in most Western European countries, AIDS incidence appears to be stabilizing, with ever lower rates of increase after 1994.

As in the other countries studies, the groups most at risk have been men who have sex with men and injection drug users. Among new AIDS cases reported to the National AIDS Centre in 1995, 88 per cent were male. Eighty-one percent were either men who have sex with men or injection drug users. Over ninety percent of new HIV infections in 1992 were in these risk categories.

(e) Summary

The HIV/AIDS epidemic in Canada can be characterized as moderately strong. While much less of a problem than in the United States, HIV/AIDS in Canada is greater problem than in many other industrialized countries, including Germany and Australia. Table 2.1 presents annual incidence and number of cases for these countries.

TABLE 2.1
Cumulative AIDS Incidence Rates (per 100,000 population), 1995

Country	Incidence Rate	Total Number of Cases
United States	15.2	513,486
Canada	3.4	13,291
Australia	2.9	6,442
Germany	1.5	14,518

Source: LCDC, AIDS in Canada, 1996, Appendix I.

2.2 Background to the Programs

In industrialized counties, national programs to combat HIV/AIDS began to be implemented in the early 1980's, with a peak number being created in 1987 or shortly after the 1987 WHO World Health Assembly. In most of these countries, a small set of common factors provided political impetus for their programs, although their relative influence varied from country to country. Chief among these factors were: 1) awareness of cases infected through the blood supply, and in many cases, concern over negligent or slow government response; 2) mobilization of community groups, particularly among gay men; 3) deaths of prominent people; and 4) awareness of cases infected through contact with health workers. The relative strength of each of these factors, especially the extent to which the gay movement was organized before the onset of the epidemic, have shaped each country's response to it. Each country's program has also been shaped by the structure of its existing health care system. In the four cases studied here, only the United States does not have a nationalized health system.

(a) Canada

The Canadian federal government has implemented two phases of a national AIDS program, called the National AIDS Strategy. Both Phase I (1990 to 1993) and Phase II (1993 to 1998) emphasized partnership among governments and other organizations, and balance between prevention, search for effective treatments, and care. These strategies followed the recommendations of a National Advisory Committee on HIV/AIDS and an Ad Hoc Task Force on AIDS formed in 1983. The objectives of Phase II of the Strategy are:

- stop the transmission of HIV;
- search for effective vaccines, drugs and therapies;
- treat, care for and support people infected with HIV, their caregivers, families and friends;
- implement NAS Phase II activities effectively.

(b) United States

AIDS was first recognized in the United States, and response in some areas, notably New York and San Francisco, was quickly mobilized. Several charitable foundations also provided funds, notably the Robert Wood Johnson Foundation, which in 1988 provided $16.6 million for community-based services in high-prevalence areas. In the mid 1980's, three major reports called for a pragmatic, balanced and coordinated approach with new resources[6]. However, the American federal government largely left the initiative to respond in the hands of state and local governments until the late 1980's. The Ryan White Act of 1990 was instituted to provide federal assistance to areas most affected by the epidemic but funds were cut back in 1991. The first American National AIDS Strategy was not launched until 1997, a decade after most other countries.

The National AIDS Strategy has six goals:

- develop effective treatments, a vaccine and a cure;
- reduce the number of new HIV infections to zero;
- ensure access for all people living with HIV to affordable, responsive high quality services;
- ensure that all people living with HIV are not subject to discrimination;
- provide strong continuing support to international efforts;
- ensure that research advances are translated into improved prevention and care.

Partnership between the public and private sectors is emphasized, and there is a relatively strong focus on civil rights.

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[6] Surgeon General's report on the Acquired Immune Deficiency Syndrome, 1986.

Institute of Medicine and National Academy of Sciences, Confronting AIDS (Washington, SC, National Academy Press, 1986, and update, 1988).

National Commission on AIDS, Report no 1, December 1989.

(c) Australia

Developing from a 1988 policy discussion paper, the first National HIV/AIDS Strategy was implemented by the Commonwealth of Australia in 1989. A second strategy, incorporating recommendations of an evaluation of the first, was implemented from 1993 to 1996. The second strategy had four components, with the following aims:

Education and Prevention Program

- ☐ to increase awareness of HIV/AIDS issues within the Australian community;
- ☐ to promote the development of community norms within populations at risk which support the establishment and maintenance of safe behaviours;
- ☐ these aims to be achieved through providing an appropriate range of public education initiatives and enabling individuals to assess their own risk and to make decisions about their behaviour.

Treatment and Care Program

- ☐ to improve the quality of the lives of those people living with HIV/AIDS through the provision of high quality, accessible and timely treatment, care, counselling and support, in a cost-effective manner.

Research Program

- ☐ to increase knowledge of ways to eliminate or limit the spread of HIV infection;
- ☐ to reduce the harm to individuals and the community resulting from HIV infection through supporting a comprehensive research program and ensuring research results are translated into practice.

International Assistance and Cooperation Program

- ❑ to contribute to limiting the incidence and impact of HIV/AIDS globally with a particular focus on the Asia/Pacific region.

The Second National Strategy calls for partnership between affected communities, governments at all levels, and medical, scientific and health care professionals. The respective roles of each group are outlined in the Strategy documents, with the federal government's role concentrated in national leadership, public education, research, and coordination and monitoring. States and Territories are responsible for planning, funding, delivery and evaluation of education, prevention, treatment and care services provided through the health care system.

(d) Germany

As a result of a coalition agreement emerging from a Conference of the Ministers of Health and the German federal government and the provinces, the German federal Ministry of Health instituted its national AIDS program in 1987: the Sofortprogramm zur Bekampfung von AIDS (Program for Immediate Assistance in Fighting AIDS, or Immediate Program). Funded from 1987 to 1991, this program had three major goals:

- ❑ minimization of new HIV infections;
- ❑ optimum counselling and care for persons with HIV infection or AIDS;
- ❑ promotion of the acceptance of and solidarity with those affected.

While the provinces are primarily responsible for prevention and health care, the federal program funded health education, pilot programs and applied clinical and social science research. Extensions of this program, with reduced funding, are still in place.

(e) Summary

These four national programs are quite similar in many respects. All contain the same basic objectives: to prevent new infections; to care for those infected; and to produce research breakthroughs for both of these. All also included an international component. However, emphasis on civil rights and on social acceptance of people with HIV or AIDS varies from country to country. In Canada, this is not an explicit focus at the level of the overall program objectives, although present in program activities. Canada's program is also the only one of the four studied to include an objective of implementing the strategy effectively.

2.3 Level of Commitment

The next variable to be examined is the level of federal government commitment to the HIV/AIDS Strategy. This is examined in two ways: in terms of financial support to the strategy; and in terms of political commitment.

(a) Canada

Canada's federal financial commitment to HIV/AIDS was $203.5 million in funding over 1993 to 1998. These funds were allocated to NAS-II, mainly through the federal health ministry, among five types of activities:

- ☐ *coordination and collaboration:* $7.5 million, or $1.5 million per year (about four per cent of program funds);
- ☐ *education and prevention:* $31 million, or $6.2 million per year (about 15 per cent of program funds);
- ☐ *research and epidemiological monitoring:* $89.2 million, or $17.84 million per year (about 39 per cent of program funds);

- *community development and support for non-governmental organizations (NGOs):* $49 million, or $9.8 million per year, (23 per cent of program funds);
- *care, treatment and support:* $26.8 million, or $5.36 million per year (about 13 per cent of program funds).

This represents roughly 40 per cent of the total expenditures on HIV/AIDS, including programs and services offered through other levels of government[7].

The Canadian federal government's political commitment to HIV/AIDS is seen as relatively strong, although many non-governmental organizations have expressed dissatisfaction with its lack of commitment to a permanent or long-term program. Other findings from the present evaluation show that, contrary to many other areas where there is federal-provincial jurisdictional tension, there is wide support for a strong central federal role in HIV/AIDS. A national advisory committee was set up with members from various stakeholders and interest groups, reporting to the Minister of Health.

(b) United States

For the 1997 fiscal year, the newly-announced American National AIDS Strategy has a total budget of $8.766 billion.

The national response to HIV/AIDS has been slower in the United States than in many other countries. The National Commission on AIDS in 1991 produced an action-oriented report, but it resulted in little action by the Executive Office. The first national coordinated program was announced in 1997, almost ten years after most other industrialized countries. Federal AIDS programming in the U.S. has been fraught with resistance from conservative politicians and right-wing church and political groups.

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[7] Unpublished data provided by the Canadian Policy Research Networks.

(c) Australia

The Second National AIDS Strategy received a total of $332.24 M (AUS) over three years. The Strategy was funded through several budgetary envelopes, making it difficult to identify spending in each of the four program components. However, it is estimated that over 1994 and 1995, about 16 per cent of funds went to Education and Prevention, while 61 per cent went to Care and Treatment and 13 per cent to research. Roughly 20 per cent of funds were allocated to federal activities, while 80 per cent were funds transferred to states and territories in a Matched Funding Program, to which states and territories contribute matched amounts. These funds take the states' populations and number of cases into account. Among the transferred funds, by far the largest share (i.e., 52 per cent of total program funds) was in the form of Medicare hospital funding grants for AIDS care. The Commonwealth AIDS Research grants fund received about $41 million, or 12 per cent of funds. Aboriginal and Island populations received about one per cent of total funds in 1994/95. A third phase is now underway, with funding in 1996/97 of $50 million.

Political commitment to a national AIDS strategy in Australia has been very strong almost since the first cases were recognized there. Australia was among the first nations to introduce the universal screening of blood supplies (April 1995) and has been generally regarded as a model of early, progressive, coordinated response. Cooperation from all provinces has been present, with roles and responsibilities clearly defined. However, because health care is a state responsibility and because there is no national epidemiological or disease control laboratory, some aspects of the Australian response have been fragmented.

(d) Germany

Germany's Immediate Response program received over 500 million DM from 1987 to 1991 (high of 123,100,000 DM in 1988) for health education, pilot programs, and applied clinical and social science research. About 50 million DM per year was available from 1992 through 1996. Of total expenditures on the federal strategy, research and development projects received a total of 98.5 million DM. Another 152M DM (about 20 per cent of program funds) were provided from 1984 to 1994 for basic AIDS-related research through granting councils.

AIDS policy in Germany has been extremely politicized. Political commitment to a federal AIDS strategy has been strong since the early days of the epidemic, although there has been some difference of opinion in the preferred strategy. Some provinces, notably Bavaria, have consistently argued for a more classical method of epidemiological control, invoking the use of public health laws that allow for mandatory testing, criminal prosecution for infectious behaviours, and investigation and regulation of individuals and sites suspected of contagion. Bavaria has thus enacted its own AIDS measures, which are considerably more controlling than those of the federal program. Because the courts have been required to adjudicate and interpret statutes in some of these political conflicts, there has been more involvement of the legal system with HIV/AIDS-related issues than in many other countries, particularly regarding legal responsibilities of those infected to prevent transmission.

(e) Summary

It is difficult to compare the level of federal commitment to AIDS programming in these countries, mainly because of their differences in terms of responsibility for management and delivery of health care and presence of nationalized health systems. However, they all have tried to balance allocations among prevention, care and treatment, and research. Degree of federal political commitment and responsiveness to HIV/AIDS has varied more significantly, with both Australia and Germany showing an earlier mobilization of federal commitment (in terms of both funding and release of a national program) than Canada, and with the United States lagging far behind.

2.4 Relationship Between Governmental and Non-governmental Sectors

Analysts of national AIDS programs (Mann *et al.*, 1993, Porter, 1994) agree that good interministerial collaboration, over and above the involvement of the health ministry, and strong participation of the non-government sector are necessary for effective national programs. Several reasons are given for this: NGO's may be more cost-effective (or simply less costly) than public services; may be more responsive to emerging needs; may be able to more effectively represent needs and values of particular groups; and have better access to target communities, especially among marginalized groups. The involvement of multiple agencies may increase diversity in program interventions, and second, may create broader and more sustainable support in the population. In a survey of 14 national programs conducted in 1992, about 15 per cent of program funds (with a range of from five per cent to 50 per cent) were allocated to NGO's (Mann *et al.*, 1992).

(a) Canada

In Canada, a cornerstone of the National AIDS Strategy was collaboration between governments and non-government organizations. Federal funding to non-governmental AIDS organizations began in 1986. In the National AIDS Strategy, Phase II, a total of 26 per cent of national program funds were allocated to non-governmental organizations. Funds were provided to both community-level groups to provide preventive and care services (seven per cent of program funds, to the AIDS Community Action Program) and to national advocacy and coordinating bodies to support their infrastructure (19 per cent of program funds). With a strong community and organizational development focus, the AIDS Community Action Program funded national, regional or local initiatives in four priority areas: prevention education, strengthening organizations, reducing barriers, and evaluation.

(b) United States

The American strategy has put relatively little emphasis on participation of the non-governmental sector, and relatively more on the private sector. However, beginning in 1994, the Centres for Disease Control have implemented a community-based program, HIV Prevention Community Planning, in which 65 health departments receiving prevention funds from the CDC identify and prioritize prevention needs in collaboration with representatives of affected groups. This component of CDC programming will receive $204 million (US) in 1997, or about two per cent of federal funds for HIV/AIDS. Community-based organizations are thus recognized as important conduits of successful HIV prevention, but there is no mention of similar involvement in care, treatment and support even though hundreds of such organizations provide such services. Some components of the CARE Act provide direct support services for people living with HIV, and some community-development block grant programs funded through the Housing and Urban Development Department may fulfil some of the community support function.

There is a strong AIDS advocacy movement in the United States, led by groups such as ACT-UP (AIDS Coalition to Unleash Power) and the National Gay and Lesbian Task Force. These groups have brought political pressure to bear against the conservative tendencies of the American government during the first decade of the epidemic.

(c) Australia

The Australian AIDS strategy has relied strongly on the concept of partnership among levels of government and with the non-governmental sector, and its evaluation recommended a continuation of this partnership approach. Key non-governmental partners in the strategy are the Australian Federation of AIDS Organizations and the Haemophilia Foundation of Australia. The former organization, established in 1985 and representing state and territorial AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Intravenous League and the Scarlet Alliance (a sex workers' organization), has received umbrella funding from the national strategy.

As in many other countries, it was gay organizations which were the first to organize and obtain financial support from the federal and state governments. Their success has been attributed to their ready state of political organization, which had been mobilized over the preceding decade to modernize homosexuality laws. Both the Catholic and Anglican churches have provided support to local AIDS Councils. The medical profession in Australia, embroiled in conflict with the government over doctors' fees and Medicare, at the beginning of the epidemic, has sometimes opposed elements of the national strategy supported by other non-government sectors.

(d) Germany

The German AIDS strategy has included partnerships with non-governmental organizations from its beginning, in order to deal directly with fears of social stigmatization and legal discrimination, especially sensitive in this country. It was explicitly stated in official program documents that such collaboration was essential to gaining trust from those afflicted, particularly in high-risk groups. The gay movement, highly organized in Germany before the advent of HIV/AIDS and well-supported politically, took the forefront with the group Deutsche AIDS-Hilfe as the main player. AIDS-Hilfe, founded in 1983, has evolved into a national coalition of AIDS service organizations, with 120 local chapters. The head office is funded through the federal AIDS program, while the local programs are generally funded through municipalities and provinces. Between 1985 and 1993, AIDS-Hilfe received a total of 47.6 million DM (about six per cent of program funds), and by 1988 had 35 full-time staff. The relationship between AIDS-Hilfe and the federal government has not always been smooth, as funding is provided on a project-by-project basis and some differences of tactic have occurred. People living with HIV/AIDS also hold regular national meetings. Registered prostitutes have also begun to organize as partners in the German program. Although attempts have been made to organize injection drug users in Junkie Associations, these have not been successful.

(e) Summary

Federal programs in three of these four countries — Germany, Australia and Canada — have developed close relationships with the non-government sector, as a function of a strong partnership orientation in their strategies. Support for both umbrella and local organizations is provided, but with other levels of government (provincial or state, regional, or municipal), also providing support to local organizations. In all cases, including the United States, these relationships have provided additional range and flexibility of intervention, sometimes allowing controversial programs to be implemented not directly by government, but with its indirect support (e.g., needle exchange programs). These relationships with the non-governmental sector, notably with gay advocacy organizations, have also allowed federal governments to demonstrate leadership in the human rights issues associated with HIV/AIDS. On the negative side, these partnerships have, in all countries studied, sometimes caused frictions between the more conservative bureaucracies and the more audacious non-government groups.

2.5 Program Management

Position within Government. In many countries, national responsibility for HIV/AIDS is located within the national health ministry, although in some cases responsibility is shared with another ministry (e.g., education), and in others a new national agency was created. Federal states (i.e, composed of provinces or states with their own levels of government) have generally adapted existing coordination and communication mechanisms between levels of government, in a multi-layered approach. Coordination and communication problems due to these layers are noted in many industrialized countries. A global tendency toward decentralization and horizontal integration is reported. Integration of STD and HIV/AIDS programs is regarded as a central issue in this tendency (Mann et al., 1992), as are links to primary care and social services.

In Canada, Health Canada is responsible for the AIDS dossier. It coordinates interdepartmental efforts (in international development, correctional services and immigration.) The federal coordination role for HIV/AIDS has undergone some reorganization, with the original Federal Centre for AIDS having been dismantled in the early 1990's and replaced by the AIDS Secretariat and finally the AIDS Policy and Coordination Unit. Within the department, the HIV/AIDS coordinating unit reports to the Assistant Deputy Minister of the Health Promotion and Programs Branch.

In the United States, coordination has been hampered by the competition between federal agencies for HIV/AIDS resources. The 1997 Annual AIDS Strategy document specifies roles for 27 federal departments, administrations, offices, commissions, agencies, services or centers, with 11 in the Department of Health and Human Services. The Strategy was developed by the Office of National AIDS Policy, created in 1993, which reports to the White House.

The German AIDS program is located within the federal ministry of health. The Coordinating Unit, in 1992 made part of an integrated "Infectious Diseases, AIDS, Addiction" division of the ministry was first staffed in 1987. It has responsibility to introduce federal AIDS programs and to coordinate these within the federal government and with provinces, districts and municipalities. Developed out of an expanded role of the AIDS Working Group, in place since 1983, the AIDS activities in the health ministry now include the national epidemiological reference and testing centres.

In Australia, coordinating mechanisms and interaction are clearly indicated in a national program document. The national program is coordinated through the AIDS/Communicable Diseases Branch of the Department of Human Services and Health.

Advisory Bodies. According to a survey conducted by the Global AIDS Policy Coalition, all countries surveyed have created a national advisory body. Often initially composed of scientists and medical personnel, their composition has evolved in many countries to include broader stakeholder representation. Most of these bodies report to the national health minister. There is some evidence that committees which report directly to the head of state are more effective (Mann et al., 1992).

(a) Canada

In Canada, the National Advisory Committee on HIV/AIDS preceded the first phase of the Strategy, replacing an Ad Hoc Task Force on AIDS formed in 1983 and reporting to the Laboratory Centre for Disease Control. It is composed of 10 members representing various stakeholder groups, including the head of the Canadian AIDS Society, a coalition of community-based organizations. Reporting to the Minister of Health, it has remained active throughout the national strategy and has had moderate influence on HIV/AIDS policy in Canada. A Federal-Provincial-Territorial

Committee, composed of representatives of health departments from all jurisdictions, has been in existence for the same time but has been relatively inactive.

(b) United States

In the United States, two main advisory bodies have shaped the newly-announced National AIDS Strategy: the Presidential Advisory Council on HIV/AIDS and the Interdepartmental Task Force on HIV/AIDS. The latter is composed of representatives from 18 departments and agencies.

(c) Australia

Following the activities of a National AIDS Task Force and the National Advisory Committee on AIDS, both established in 1984, the 1985 Australian Health Ministers' Conference endorsed the National Health Strategy for AIDS Control, and funding to community-based organizations and state and territorial governments began. In 1988, the AIDS Task Force and the National Advisory Committee were replaced by the Australian National Council on AIDS. With expertise in medicine, science, law and public policy, the Council's continuing role is to identify national needs, objectives and priorities and to provide information to the public. The Intergovernmental Committee on AIDS is composed of representatives from state, territorial and federal governments. It is regarded as an effective forum for coordination and planning within Australia's federal system.

(d) Germany

The German AIDS program in the federal health ministry is advised by a national independent advisory committee, established in 1984 and composed of representatives from various medical and social service professions as well as AIDS service organizations, churches, pension and health insurance funds, employer and employee associations and the provinces. This committee holds regular meetings, voting on important policy issues (e.g., mandatory HIV testing) and publishing the results. An Interministerial Working Group was established in 1987 to coordinate AIDS activities between federal departments.

Several provinces and major urban centres established comprehensive AIDS programs early in the epidemic. Regional programs were also established in new provinces following the unification of Germany. Coordination between the federal and provincial governments is facilitated by several bodies, including working groups of senior medical officials and of epidemiological experts from all health ministries, and a federal/provincial committee for coordinating AIDS education programs. The Conference of Ministers of Health was influential in the basic design of the federal strategy and has continued to endorse the overall approach.

(e) Summary

The structures and reporting relationships of these federal AIDS strategies have all been determined by those existing for the health system in their respective countries. In Canada, Australia and Germany, health care delivery is a provincial or state responsibility but a federal entity provides policy, coordination and funding. The AIDS programs have been closely associated with this federal body, and have made use of existing mechanisms for federal-provincial coordination, notably conferences of health ministers. Of these three, Australia seems to have been the most successful, and Canada the least, at ensuring clear division of responsibility. In all countries, national advisory bodies with broad representation have been set up, and all have played major roles in the development of policy.

2.6 Response in Prevention

According to analysts of national AIDS programs, adequate prevention response should include activities including information diffusion and awareness, education and preventive services (Mann *et al.*, 1992). Moreover, it is generally believed the use of diverse strategies will be associated with greater effectiveness.

(a) Canada

The prevention activities of Canada's national strategy have been concentrated in two of its 16 components, the Education and Prevention Unit and the AIDS Community Action Program. The Education and Prevention Unit, which received about 15 per cent of program funds, aimed to facilitate and coordinate preventive education programs undertaken by a network of partners. The intended focus of these activities was behavioral change among vulnerable populations, including aboriginal people, injection drug users and their sexual partners, populations in correctional facilities, street-involved youth, and gay and bisexual men. In addition, a substantial portion of the 23 per cent of funds directed to community-based organizations have been allocated to awareness, education, and knowledge development (up to 1992, 35 per cent of these funds had been directed to these activities). These groups established local education and prevention initiatives, sometimes with support from other levels of government.

Canada's Strategy has made a specific commitment to education and prevention in its aboriginal population for which it holds responsibility for health.

(b) United States

The prevention program in the United States will focus on: epidemiological monitoring and risk factor research; research on effective prevention interventions; strengthening community-based programs through community prevention planning supported by the Centres for Disease Control; and integration of HIV prevention with other disease prevention efforts. A strong connection is made between prevention and primary care; this link is facilitated by the federal mandate in health and public health insurance programs. Vulnerable populations to receive special attention are adolescents (especially gay young men), women, minorities, gay men of colour, substance abusers, and prisoners. Note that current federal law does not allow use of federal funds for needle exchange programs; where these have been implemented, it is with state or local funds.

The total federal budget for prevention is impossible to assess, as many activities are financed through regular operating budgets (for example, in the comprehensive school health program funded by the Department of Education). The total of identifiable expenditures is about $700M, or slightly less than one-tenth of the overall budget. Of this, $204M per year is provided to the CDC for HIV prevention programs which may be carried out through direct funding to state and local health departments and community-based groups.

(c) Australia

Australia's national AIDS strategy has taken a central role in public and risk-group education. The Education and Prevention Program, with a total funding allocation of 16 per cent of the total budget, has four main objectives: to improve knowledge of risk behaviours and skills in the assessment of risk; to facilitate and promote access to voluntary testing and preventive measures and programs; to help people living with HIV/AIDS make informed decisions about their health and treatment; and to reduce myths, unnecessary fears and discrimination. Five priority groups were identified: homosexually active men (highest priority); injecting drug users and their sexual partners; aboriginal and Torres Strait Islander people; people living with HIV/AIDS; and a host of other groups, including sex workers, prisoners and youth. Estimates of effectiveness of prevention programs for homosexually active men and injecting drug users (needle exchanges) suggest that both have reduced HIV incidence. At the national level, education and prevention focused on caregivers for people with HIV/AIDS, and community education. School-based HIV/AIDS education was considered have a great prevention potential, and by 1994 significant increases in the proportion of children in grades five to 12 receiving HIV/AIDS education had occurred. HIV testing is widely available through physicians, sexual health clinics, community health centers and hospitals, with federal support through the Matched Fund Program.

(d) Germany

Prevention programming in Germany has focused on: education, counselling, targeted HIV testing and protective products and hygiene measures. Educational measures received about 37 per cent of Immediate Program funds, and has financed both public and targeted HIV/AIDS education, some through AIDS-Hilfe. A particular focus on youth was maintained through a "Young People and AIDS" program between 1989 and 1992. Five provinces implemented an AIDS prevention program for young people and adolescents in 1991, with emphasis on professional (teacher and social worker) training, peer education, media use, and collaboration among all institutions or services for youth. The program enabled the hiring of an AIDS specialist in all 309 Health Offices of the pre-unification Germany, as well as streetworkers in 26 cities, and 27 positions in drug counselling centres. Free, anonymous testing is made available through health centres and private centres. Low threshold drug abuse services integrate AIDS prevention, and in all but two provinces needles are available through pharmacies, drug counsellors, vending machines and community-based needle exchange organizations.

(e) Summary

With similar epidemics, these four countries have made similar responses in prevention, to roughly the same target groups. However, their relative contribution to prevention as opposed to other program goals seems to vary substantially (although these figures should be taken only as very broad estimates): Germany has made the greatest relative investment in prevention, the U.S. the smallest, with Canada and Australia lying in between.

2.7 Response in Care and Treatment

The adequacy of response in care and treatment, including medical and social services is next to be examined. Of particular interest here is how these countries have chosen to position HIV/AIDS care and treatment in the context of their existing health systems.

(a) Canada

In Phase II of the National AIDS Strategy, the AIDS Care, Treatment and Support Unit received $26.8 million, or $5.36 million per year: about 13 per cent of program funds. The focus of these activities was on building capacities to improve the quality of life of people living with HIV disease and AIDS, by strengthening formal health and social service systems as well as informal caregivers and support providers. Developed through this program were comprehensive guidelines for care and treatment of people living with HIV/AIDS, to be used as resources by both professional and non-professional providers. In addition, funding to community-based organizations was designed to facilitate access to care and support, but because health care is a provincial responsibility, the AIDS Community Action Program excluded support for direct health and social service delivery. Direct medical care and treatment for those affected are delivered by the provinces, aided by general health and social program transfer payments from the federal government. The Canadian federal strategy contains no explicit links to health care delivery systems. A Clinical Trials Network, aiming to attract pharmaceutical trials to Canada in order to both help develop new treatments and improve accessibility of new treatment to Canadian living with HIV, was funded through this program, as was the AIDS Treatment Information Network, an information resource for professionals and people living with HIV/AIDS.

(b) United States

The total federal contribution to care and services in the National Strategy is $5.5B (US), including social security and social security disability pensions. Because there is no national health insurance plan in the United States, the availability of medical services for people with HIV disease is a more important problem than in Canada or our two other comparison countries. About 55 per cent of adult Americans with AIDS receive services funded through the federal health insurance programs for eligible individuals without private insurance (Medicaid or Medicare). About 15 per cent of people living with AIDS have private insurance, while the remaining third have no insurance. The Ryan White Comprehensive AIDS Resources Emergency Care Act of 1990, administered by the Health Resources and Services Organization was intended to fill gaps in coverage. Funding for this act has been increased to $996M in 1997, and extended to 2001. The care and services component of the American national program does not include work undertaken by community-based groups.

(c) Australia

The objective of the Treatment and Care program of the national strategy is to improve the quality of the lives of those people living with HIV/AIDS through the provision of high quality, accessible and timely treatment, care, counselling and support in a cost-effective manner. According to the strategy evaluation, this federal component is likely to be wound down in the future. Australia maintains both a national health insurance program and a Pharmaceutical Benefits Scheme, which ensures access to medical treatment and drug treatment for all Australians living with HIV/AIDS. Moreover, the national strategy explicitly assumes that the mainstream health system, delivered by the provinces, should be primarily responsible for care and treatment. About $175 million was provided to hospitals for AIDS inpatient care through Medicare Hospital Funding Grants during the second national strategy. Through the Matched Funding Program, a total of $24.6 million (including both state and federal contributions) was provided for outpatient and community support for people living with HIV/AIDS. These funds were allocated most frequently to hospital outpatients programs, AIDS/STD clinics, non-profit organizations, or community health centres.

(d) Germany

Medical care and treatment for Germans living with HIV/AIDS is provided by university-based clinics and hospitals. In 1987, 45 million DM were provided to improve the infrastructure for in-patient AIDS care. These services are now funded through regular operating budgets paid by the health insurance organizations. A clinical treatment and research network funded by the program groups about 30 treatment centres in seven regions. Expansion of the treatment program is foreseen. Outpatient care has been supported through the program's financing of 200 nursing and social work positions in 75 locations in the country for outpatient and home care. These services are also provided by AIDS service organizations funded through the program.

(e) Summary

All four countries have attempted to develop or reinforce health system infrastructures to ensure that people living with HIV/AIDS have access to comprehensive and high-quality care, treatment and support. In the United States, the combination of a lack of a nationalized health system and the concentration of the epidemic among those without private health insurance has created some barriers to access. In Germany and Australia, program funds have been delivered directly to existing health infrastructures in order to improve access to and quality of treatment and care. In Canada, this response has been much more indirect, as the federal strategy actually excludes federally-supported action on matters in provincial jurisdiction.

2.8 Research

Commitment to research in federal programs has aimed to improve intervention at all levels, both within the research sponsor's country and by contributing to international research efforts.

(a) Canada

The Canadian research effort includes programs funded through two competitive research agencies and through the ministry of health. Excluding support to the Clinical Trials Network and the epidemiological surveillance activities carried out within Health Canada, about $12 million per year, or about 28 per cent of program funds, are spent on research. As well as supporting the Clinical Trials Network, Canada's AIDS research program includes biomedical, clinical, epidemiological, behavioral and social research into HIV/AIDS prevention and treatment. Laboratory and clinical research on AIDS vaccines and treatments is also carried out within the Health Protection Branch of Health Canada.

(b) United States

The United States has mounted a huge research effort. The total budget request for 1996 from the Office of AIDS Research of the National Institutes of Health was $1.43B (US). This was spent in the following areas: natural history and epidemiology (13 per cent); etiology and pathogenesis (26 per cent); therapeutics (35 per cent); vaccines (eight per cent); behavioral research (11 per cent); and training, infrastructure, information and dissemination (five per cent). Of the total budget of the National Institutes of Health, 12 per cent is now devoted to AIDS research. An additional $75M is spent on research through other federal departments and agencies, notably the Food and Drug Administration. The U.S. commitment to AIDS research is therefore about 17 per cent of the total program funds.

(c) Australia

Australia's national AIDS program devoted about 13 per cent of its funds to research. Support is provided through project grants, training awards, and to three national research centers: in virology research, HIV epidemiology and clinical research, and HIV social research. The latter program operates three streams, focused on men who have sex with men, people living with HIV/AIDS, and the general population with emphasis on youth. Originally a separate entity, the Commonwealth AIDS Research Grants program has now been incorporated within the National Health and Medical Research Council. Virological and social/behavioral research have received most program funding through this program, with relatively little emphasis on epidemiological and clinical research. However, the national strategy also supports a network of clinical trials centres.

(d) Germany

The German AIDS program sponsors basic clinical and social research related to HIV/AIDS, administered through the federal AIDS program. From 1983 to 1994, the AIDS basic research infrastructure was developed, mainly through 152M DM of funding (about 20 per cent of program funds) provided by the federal Ministry of Research and Technology until 1994. The Immediate Program and its successors provided a total of 98.5 million DM for research and development (17 per cent of funds). Behavioral research has been a focus since 1989. The Paul-Erlich Institute, part of the federal AIDS unit, performs research on the development of diagnostic tests as well as experimental and clinical vaccine research.

Summary

All of the countries studied have allocated significant resources to HIV/AIDS research in the complete spectrum of research domains. Although the United States has made the largest absolute commitment to research, Canada's proportional investment in research is somewhat greater than that in other countries.

2.9 Sustainability

The sustainability of national AIDS programs is a greater issue in developing countries, particularly in Africa, where the combination of limited collective wealth and a more stronger epidemic raise serious questions about central governments' capacities to continue to respond to the epidemic. Nevertheless, sustainability of national AIDS programs in industrialized countries is also of interest, because economic pressures and ideological differences regularly cause all such investments to be requestioned. Given the worldwide tendency of mainstreaming AIDS programs, sustainability may also come to be synonymous with degree of integration into existing health, social service, and research systems.

(a) Canada

The sustainability of Canada's national AIDS strategy beyond its time-limited funding horizon is not guaranteed. A preliminary announcement for a third phase of funding is contingent on developments in the newly re-elected federal government. As provincial governments have been supplying an increasingly large portion of total HIV/AIDS funding in Canada, the sustainability of federal programming will likely reflect renegotiation of federal-provincial roles in both prevention and treatment. Buy-in from the provincial governments has been mixed.

(b) United States

The American situation differs from those in the other countries studied here, insofar as the epidemic is clearly worse in the United States and is affecting disproportionately that part of the population which is dependent on the federal government for access to services. While it is too soon to speculate about the sustainability of the American program, it can be said without much doubt that HIV/AIDS will be a major preoccupation for the American government for some years to come. Political buy-in is not guaranteed, as the right-wing movement is still quite powerful in American government.

(c) Australia

Australia's HIV/AIDS program, now into its third multi-year funding period, seems likely to be sustainable. With the exception of aboriginal populations, the epidemiological situation in Australia seems to be stabilizing, suggesting that resource commitment may also be able to stabilize. Moreover, the clear division of responsibilities between the federal and state governments has allowed the Commonwealth to pull back its investment in care and treatment. Buy-in from all parties — other levels of government, community-based organizations — is strong.

(d) Germany

Despite the generally stabilizing epidemiological picture emerging from Germany, some aspects of the German situation would potentially limit the sustainability of the national program. On the positive side, efforts have been made to integrate HIV/AIDS resources permanently into the health and social services systems. Horizontal integration of low-threshold and AIDS prevention programs for injection drug users are another example of sustainable efforts. However, the existence of dissident ideologies, notably in Bavaria, suggests that buy-in is incomplete and that the federal approach may yet be contested.

(e) Summary

Because these nations are relatively wealthy, sustainability of a federal investment in HIV/AIDS programs is unlikely to be threatened by lack of resources. Rather, sustainability is more likely to be a function of political choices, support from other levels of government, and long-term integration into existing health system structures. In this respect, Australia, and to some extent Germany, have been able to more explicitly delineate the boundaries of federal-provincial responsibility, and so have advanced farther into the sustainable integration of AIDS activities in the existing health and social services systems than have either Canada or the United States.

2.10 Evaluation

A survey of national AIDS programs conducted by the Global AIDS Policy Coalition (Mann *et al.*, 1992) revealed that only about half of the programs in industrialized countries had been evaluated. In most cases, evaluation was conducted by national staff, with rare international participation.

(a) Canada

Although the first phase of the Canadian AIDS Strategy was not evaluated, the second phase called for called for an evaluation framework, carried out in 1993-94, and a final evaluation. In addition, a mid-term review was carried out in 1995-96. Project evaluation is identified as a requirement of funding to community-based groups, but the level of compliance and sophistication of these local efforts varies greatly. Epidemiological surveillance is conducted by the Laboratory Centre for Disease Control, located within a parallel unit of Health Canada.

(b) United States

All components of the national strategy call for ongoing monitoring and program evaluation, in order to improve accountability and priority setting. National epidemiological surveillance is maintained by the Centers for Disease Control and Prevention, a federal institution under the Department of Health and Human Services.

(c) Australia

The first Australian National AIDS Strategy was evaluated, and recommendations incorporated into the design of the second. The second strategy has also undergone an intensive evaluation, under the direction of an international researcher but conducted by staff of the Department of Health and Human Services. Many of the recommendations in this evaluation call for development and implementation of adequate performance indicators to measure outcomes.

(d) Germany

The German program has a strong evaluation component, with funding for the evaluation of all pilot programs and most specific initiatives. Population surveys and targeted comparative surveys are routinely conducted. An Enquete Commission conducted in 1988 and released publicly in 1990 assessed the overall progress against the epidemic. Epidemiological surveillance is carried out by a specialist department within the federal AIDS Centre.

(e) Summary

All of the countries studied have made commitments to conducting evaluations of both progress and outcome. To date, Australia and Germany have produced evaluations of their national strategies. Canada is in the process of conducting a final evaluation of Phase II of its Strategy, following the development of an Evaluation Framework developed in 1993/94 and a Mid-Term Review conducted in 1995/96.

CHAPTER

3

DISCUSSION AND CONCLUSION

These four national programs are quite similar in many respects. All contain the same basic objectives: to prevent new infections; to care for those infected; and to produce research breakthroughs for both of these. Responses in prevention have been similar, using a mix of educational and community development methods, often in partnership with community-based organizations growing out of gay community groups. Access to HIV testing, while not ideal everywhere, is generally without barriers. Responses in care and treatment have also been quite similar, aimed at providing a spectrum of adequate care while not excluding people from access to the best possible treatments.

In assessing the overall relative adequacy of the strategies, it seems that Canada is neither in the best nor the worst position. Of the four countries studied, the United States clearly has the greatest remaining challenges to face in dealing with HIV/AIDS. Compared to Canada's response, these greater challenges are due to: a very late federal response; the lack of a nationalized health care system; a huge and uncoordinated federal health system; and unconquered opposition to liberalized prevention programming within government. The American federal program has also been less likely to capitalize on partnerships with non-governmental organizations.

Both the Australian and German strategies were introduced sooner than the Canadian strategy, and in the case of Australia, considerable advance planning had preceded the arrival of the epidemic. Australia, and to some extent Germany, have been able to more explicitly delineate the boundaries of federal-provincial responsibility, and so have advanced farther into the sustainable integration of AIDS activities in the existing health and social services systems. However, all three of the Canadian, German and Australian programs (but particularly the German), have been highly successful in working with community-based groups.

In terms of this comparative analysis, Canada's National AIDS Strategy-Phase II is distinguished positively by its partnership approach, as well as by its relatively great investment in HIV/AIDS research.

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 6:
Canadian HIV Trials Network Case Study

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 6: Canadian HIV Trials Network

Methodology

This report on the Canadian HIV Trials Network (CTN) is based on a case study conducted with the organization (including key informant interviews and review of documentation). As well, the views of other stakeholders have been canvassed through the other evaluation components to provide a broader view of the organization. These results have been integrated where appropriate.

Objectives

The Canadian HIV Trials Network (CTN) is a non-profit organization funded by the National AIDS Strategy which aims to develop treatments, vaccines and a cure for HIV disease and AIDS through the conduct of scientifically sound and ethical clinical trials. The mission of the CTN is "to contribute to the global understanding of HIV/AIDS and to find effective treatments and vaccines. We are committed to the pursuits of scientific excellence and ethical integrity in all undertakings. We are also dedicated to working in partnership with the international and national pharmaceutical industry, people living with HIV/AIDS, researchers and physicians".

The objectives of the CTN are:

- ☐ to seek out opportunities for Canadians to participate in collaborative research on national and international bases; and
- ☐ to enhance communications among Canadian researchers, clinicians, the pharmaceutical industry and people affected by HIV in order to foster an environment in which trials for HIV/AIDS can thrive.

The CTN contribution agreement under NAS-II was signed in October, 1994.[1] The contribution agreement allocated $2.9 million annually to the CTN over five fiscal years. Health Canada recently announced renewed funding for the organization for an additional two years at a reduced funding level of $2.5 million per year. The CTN is jointly sponsored by the University of British Columbia and St. Paul's Hospital in Vancouver.

Structure

The CTN is a national organization which is based on a de-centralized model. The national office, located in Vancouver, is responsible for the administration of the infrastructure (including liaison with industry partners and principal investigators) and data management. The Vancouver office has a staff of approximately 30 technical and administrative personnel. The bulk of CTN funding (about 80 per cent) is allocated to personnel salaries and benefits. A management committee composed of national centre program heads oversees the day-to-day operation and funding decisions of the CTN.

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[1] The CTN has been operating since 1991 with a funding agreement under the first National AIDS Strategy. The CTN model was selected based on proposals requested by Health Canada for an AIDS clinical trials infrastructure.

The national centre is comprised of five programs:

- ☐ *scientific and industrial liaison*, responsible for consultations with the pharmaceutical industry and support of principal investigators to develop funding for clinical trials;
- ☐ *administration and finance*, responsible for the general operational and financial management of the CTN;
- ☐ *communications and information*, including public relations and dissemination of information activities;
- ☐ *data methodology*, involving conduct of data collection, data analyses and methodological support as requested; and
- ☐ *pharmacoeconomics*, study of costs and cost-effectiveness of HIV/AIDS drug therapies.

Six regional offices in five regions (two regional offices are located in Ontario) provide expertise and support to the HIV research community in their respective areas. The regional offices also support and administer the clinical trials in satellite research sites in their area. There are about 30 satellite sites located in clinics and hospitals that have been involved in CTN-affiliated clinical trials. Individual trials are the responsibility of the principal investigators.

While the de-centralized structure was a requirement in the original government solicitation for proposals for a clinical trials infrastructure, the model has presented challenges for the CTN. Communications among the National Centre, regions and satellite sites can be awkward and time-consuming, and there have been tensions between the National Centre and regions around management and funding issues. Regions outside of the Pacific have not fully utilized the services provided by the National Centre and, while there are regional representatives on all national committees, the day-to-day management of the CTN, including funding decisions, are centralized, being made by program heads at the National Centre. This has been a source of frustration for some regional representatives. Ultimately, however, the de-centralized structure is viewed as having clear advantages for the CTN in terms of capitalizing on local expertise and providing greater responsiveness to local conditions.

The CTN has five standing committees which oversee the CTN infrastructure. As outlined in CTN documentation, the committees and their roles and responsibilities are as follow:

- ☐ *The National Steering Committee* acts in an advisory capacity to all Network programs and clinical trials. This committee establishes research priorities and monitors the national and international research environment. This pivotal committee also considers recommendations from other standing committees.
- ☐ *The Scientific Review Committee* provides peer review of proposals submitted to the CTN. Evaluating the scientific merit of both the therapy and the protocol design is intended to ensure each trial is methodologically sound and ethically relevant.
- ☐ *The Safety and Efficacy Review Committee* provides independent monitoring of study progress with respect to safety and efficacy. Acting as an advisory body to the sponsor and investigator, the committee can review interim analyses, recommend changes in protocol or procedures or the termination of a trial based on new information.
- ☐ *The National Ethics Review Committee* offers ethical review for sites that do not have Institutional Review Boards. This committee helps the CTN extend its trials outside of traditional institutions and into community-based settings.
- ☐ *The Community Advisory Committee* advises the Steering Committee as to the priorities, needs and concerns of HIV positive Canadians as they relate to clinical trials. It also provides advice to the Scientific Review Committee and pharmaceutical companies on the views of the community as they relate to specific protocols.

Activities

CTN activities may be grouped into four categories: clinical trials; associateships; workshops; and communications and information. Each of these are described in more detail below.

Clinical Trials

The *raison d'être* of the CTN is to facilitate the conduct of clinical trials in Canada. The trials affiliated with the CTN are typically phase II trials (small sample size trials to study side effects and beneficial effects over a few weeks or months) and phase III trials (larger sample size trials to examine lower incidence side effects or effects over a longer period of time). Clinical trials focus on anti-HIV therapies or drugs to control HIV-related disease and infections. The CTN has also been involved in a limited number of compassionate access or open label trials where pharmaceutical companies authorize the release of a limited supply of a drug to patients typically with fewer restrictions than a clinical trial. Compassionate release trials are not considered to be true clinical trials and are viewed to some extent as "pre-marketing" on the part of pharmaceutical companies for drugs that will be imminently released. Exhibit 1 provides an overview of the types of CTN-affiliated clinical trials that have been completed.

Clinical trials that are affiliated with the CTN are initiated in most cases by pharmaceutical companies or investigators. The CTN has also taken a proactive approach, however, in the development of clinical trials protocols. For example, the organization has conducted a number of workshops designed to begin the development process toward clinical trials protocols. As well, the CTN solicits Letters of Intent on an annual basis from HIV/AIDS researchers.

EXHIBIT 1
Types of Trials Completed

Types of Trials	Number of Completed Trials
Anti-HIV	
Monotherapy	5
Combination Therapy	10
Vaccine	1
Opportunistic Infections (e.g., mycobacterial infections, PCP, Kaposi's sarcoma, oral candidiasis)	19
Pediatric	2
Compassionate Access Trials	2
Total	39

Source: Canadian HIV Trials Network, Administrative Data, December 1995-April 1997.

Begun in 1994, the Letter of Intent process is designed to respond to research priorities that are identified by Canadian researchers and community groups. The CTN provides resources to support and develop protocols for selected research ideas. Most recently, for example, the CTN requested concept ideas focusing on drug management questions that are not likely to be addressed by the pharmaceutical industry. Since 1995, the CTN has received 23 Letters of Intent which are assessed based on their scientific value and feasibility. Once accepted, the CTN assists the principal investigator in the development of a full proposal and in searching for financial sponsorship from the pharmaceutical industry or granting agencies. A special project grant is awarded to the successful applicant to hire a researcher to assist in the protocol development work.

The CTN ensures a high standard of scientific quality for its approved trials through a peer review process. All clinical trial submissions to the CTN are reviewed by the Scientific Review Committee (to examine scientific validity, clinical relevance and adherence to ethical standards). The Safety and Efficacy Committee provides ongoing monitoring of trials to ensure continued relevance. Members of both committees are recognized experts in the HIV/AIDS research field, representing a variety of institutions, regions and medical specialties. Finally, protocols submitted to the CTN may also be reviewed by the Community Advisory Committee and/or the National Ethics Review Committee depending on the need or at the discretion of the sponsor.

Investigators and sponsors of trials affiliated with the CTN have access to a number of services provided at no cost. These include, for example, in-house protocol development, assistance with submissions to Health Canada, data management and input from the HIV positive community. In some instances, investigators may also apply for some supplementary funding from the CTN. The sponsor or principal investigator of the trial retains control over the conduct of the trial and ownership of the data. No information was available from the CTN on the level of services provided to CTN-affiliated clinical trials.

The CTN partners with a broad range of organizations and individuals. Representatives on CTN committees include clinical physicians, researchers, pharmaceutical company representatives, persons living with HIV/AIDS and government representatives. Community advocates are also represented on the Community Advisory Committee. Hospitals and community-based treatment centres are involved in the CTN as satellite sites.

There is also significant collaboration and contribution with international partners. Just under half (46 per cent) of network-affiliated trials have involved international collaboration. The CTN is also in the early stages of a collaborative clinical trial with the Community Programs for Clinical Research on AIDS (CPCRA) in the United States (the first large-scale collaboration). The trial will test the effectiveness of two protease inhibitors: ritonavir and a newer drug called nelfinavir. Seventeen sites in Canada will participate, enroling 400 volunteers.

As of April 1997, the CTN had received 104 submissions for clinical trials, of which 89 were complete submissions. Of the 89 completed submissions, 70 were approved by the CTN. Thirty-seven trials have been completed or have been terminated and 19 were withdrawn or cancelled. There are 18 submissions that were not accepted by the CTN and one submission is under review. There are currently 11 clinical trials that are enroling patients and three that are pending onset.

The regional distribution of protocol submissions (based on the region of the principal investigator) reflects the geographic profile of the epidemic (Exhibit 2). Relatively few clinical trials have been led by investigators in the Atlantic or the Prairies. Ontario is most active with 19 studies conducted to date, followed by British Columbia (14) and Quebec (11).

The number of protocols approved from year to year varies widely from a high of 18 protocols in 1994 to a low of 7 is 1993 (Exhibit 3). This variation seems to be linked to the funding approval process, with the number of clinical trials approved being lower when the extension of funds is uncertain.

In total, there have been just over 6,000 participants in CTN-affiliated clinical trials.[2] There has, however, been a steady decrease in the number of participants enroled in clinical trials over the past 10 to 12 months. For example, in April 1996, over 800 participants were active in CTN trials compared to just over 400 in January 1997. As of April 1997, there were about 330 participants actively enroled in clinical trials, with the bulk being in Ontario, Quebec and British Columbia (Exhibit 4). The decline in participation may be the result of recent uncertainties in the extension of funding for the CTN and, consequently, the reluctance of sponsors or the CTN to commit to protocols with longer timeframes. The recent announced CTN-CPCRA clinical trial will likely increase the level of participation to usual levels.

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[2] Note that "participants" are not necessarily individuals. Confidentiality requirements mean that the CTN has no knowledge of participants, and individuals can have participated in more than one clinical trial.

EXHIBIT 2
Protocol Development: Regional Distribution

Region of PI	Protocols Submitted	Studies Conducted (including completed and in progress)
Atlantic	5	1
Quebec	21	11
Ontario	40	19
Prairies	10	4
Pacific	29	14
Total	104	49

Source: Canadian HIV Trials Network, *Report on the Operation of the Network's Regions and Satellites*, April 1997.

EXHIBIT 3
Protocol Approvals Over Time

Year	Number of Protocols Approved
1990	11
1991	6
1992	11
1993	7
1994	18
1995	8
1996	10

Source: Canadian HIV Trials Network, Trials Approved and Implemented between 1990 and 1996.

EXHIBIT 4
Enrolment in CTN Clinical Trials
(as of April 1997)

	Total Active Enrolment in all Trials	Total Ever Enroled in CT Trials
Pacific	65	1267
Prairies	22	475
Ontario	126	2626
Quebec	98	1457
Atlantic	20	252
Total	331	6,092

Source: Canadian HIV Trials Network, Enrolment Data for CTN-Affiliated Trials, April 1997.

Associateships

Each year three associateships in the amount of $45,000 are awarded by the CTN to promising new HIV researchers. Under the supervision of an experienced trialist, the selected candidates gain practical experience in the conduct and analysis of clinical trials. Ultimately, the associateships are designed to enhance the cadre of Canadian AIDS researchers. A sub-committee of the CTN Steering Committee is responsible for the annual selection of associateship candidates.

Workshops

The CTN sponsors several workshops each year on topics of interest to HIV/AIDS researchers and others interested in clinical trails (e.g., the HIV/AIDS community, pharmaceutical company representatives). Workshops are designed to disseminate research findings, identify emerging research issues, educate study co-ordinators and the community about clinical trials, exchange ideas and information and may also result in the development of a clinical trials protocol. The CTN has also sponsored workshops to develop treatment guidelines based on the results of clinical trials. The CTN often partners with other organizations such as Health Canada, pharmaceutical companies, and provincial governments to sponsor these workshops.

Examples of recent workshops sponsored by the CTN include:

- ☐ Development of Oral Candidiasis Protocols (1996);
- ☐ Activist training seminar (1996);
- ☐ Ethical Conduct of Community Based Trials (1996);
- ☐ Cervical Dysplasia Study in HIV Infected Women (1995);
- ☐ Antiretroviral Intervention in Early HIV Disease (1995);
- ☐ Nutrition and Wasting Disease Workshop (1994);
- ☐ Vaccine Development Symposium (1994); and
- ☐ Women and HIV/AIDS Clinical Trials (1992).

Researchers from the CTN also actively participate in national and international conferences such as the Canadian Association for HIV Research Sixth Annual Canadian Conference on HIV/AIDS Research held in Ottawa in May, 1997.

Communications and Information

The CTN has a number of communications objectives. These include: dissemination of clinical trials information to HIV/AIDS patients and family physicians; and providing access to information about clinical trial results. Early in the life of the organization, the CTN struggled to raise awareness of its activities among its varying constituents and to overcome some of the misperceptions of the organization that had developed. For example, there were initial expectations among the HIV/AIDS community that the role of the CTN was to provide patients with access to investigative drug therapies. In order to attract clinical trials to the organization, it was also necessary to effectively market the services of the CTN to the pharmaceutical industry.

To increase the visibility of the CTN to individuals, physicians, the industry and community-based organizations, the CTN has developed a broad communications strategy, targeting activities to the CTN's different "markets". For example:

- ☐ To determine the needs of physicians, the CTN undertook a survey of general practitioners about the services and materials pertaining to clinical trials they would find most useful. Tailored HIV clinical trails information packages were forwarded to all GPs who participated in the survey.
- ☐ For individuals living with HIV/AIDS and community-based organizations, the CTN worked with the Canadian AIDS Society to publish a pamphlet, *Four Questions and Answers: Testing New Treatments for HIV/AIDS in Canada* which describes clinical trials and why they are important, the role of the CTN and how to learn more about HIV clinical trials. A *What You Need to Know* booklet was produced in 1996 through a joint effort with the Canadian AIDS Society. The booklet provides basic information to educate persons with HIV/AIDS about clinical trials. The booklet "explains the purpose of clinical trials, how they are conducted, how people can join a trial and what they can expect from a trial if they decide to participate".
- ☐ To promote the CTN to the pharmaceutical industry, the CTN developed a brochure, *CTN Networking*, which describes the services which are available to companies whose trials are conducted through the CTN and biographies of National Centre personnel.

The CTN has adopted a "plain language" policy and provides one-page summaries of all trials and trial results in language that is accessible to the broadest possible audience. The communications and information dissemination strategy also includes other ongoing and one-time strategies such as: the annual review publication, speaking engagements, advertisements, public service announcements and posters.

As part of its services, the CTN has provided information to HIV/AIDS patients and the medical/research community on clinical trials and treatment information. Inquiries may be received through a telephone call, visit, fax, electronic mail or letter where one or more comments are made or questions asked. The number of inquiries received by the CTN has increased steadily since 1992 from 220 in 1992 to 681 in 1995 (1996 figures were not available) as the need for and visibility of clinical trials has increased.

The most significant increase in activity was between 1994 and 1995 with requests for information almost doubling, largely as a result of the creation of the CTN's web site and requests via Internet electronic mail. In fact, the CTN tracking of requests indicates that 44 per cent of individuals found out about the CTN information services through Internet sources. The bulk of requests for information come from British Columbia (38 per cent), Ontario (31 per cent) and Quebec (19 per cent). The most frequently asked for information was Canadian clinical trial information, drug information, AIDS related questions and requests for publications.

Prior to last year, the CTN was one of the few sources of information in Canada about treatments for HIV/AIDS. With the establishment of CATIE's AIDS Treatment Information Network, the requests for treatment information from the CTN have decreased. The CTN now works closely with CATIE to distribute information about clinical trials. Up until April 1997, the CTN produced the *Directory of HIV Clinical Trials in Canada* which provided summary information (title, principal investigator, sites, treatment, sponsor, purpose, enrolment information and inclusion/exclusion criteria) of CTN and non-CTN-affiliated clinical trials in Canada. The directory was based on a survey of pharmaceutical companies and principal investigators in Canada and was produced on an annual basis. This has now been replaced by a more concise "Currently Enroling Trials" sheet that is compiled every two months so that information is more current. This sheet is produced in collaboration with CATIE.

An important source of information for the HIV/AIDS community and researchers/physicians is the CTN's web site. The web site provides information on currently enroling clinical trials, how to register and trial result summaries. CATIE's web site provides a link to the CTN for information on ongoing clinical trails and the CTN is also linked to other web sites such as HIVPOSITIVE in the US.

The communications activities of the CTN have been relatively successful in reaching community-based organizations, based on the results of our survey. The majority of stakeholder groups (69 per cent) were aware of the Canadian HIV Trials Network. Of those organizations that stated that they were aware of the CTN, most (62 per cent) stated that their organization or its clients had needed services like those provided by CTN. This was significantly higher among community organizations (70 per cent) compared to 38 per cent of professional associations. Seventy-two per cent of organizations who needed services like those provided by the CTN have had or currently have clients participating in CTN-affiliated clinical trails.

Continued Need and Relevance of the CTN

Since the CTN was established in 1991, the organization has seen an evolution in its role and contribution. In light of the rapidly changing environment, the CTN undertook a strategic planning exercise to re-evaluate the future directions of the organization. A series of planning sessions were held with pharmaceutical company representatives, government, people living with HIV, regional directors and investigators. At issue was the need to clarify the mission of the CTN, to improve operations and better serve stakeholders. The strategic review also focused on ways to expand the funding bases of the CTN and set concrete objectives for the future.

While the facilitation of clinical trials continues to be the main focus of the CTN, the organization has also responded to other issues which have been found to be related to the conduct and/or consequences of clinical trials. Issues which were not foreseen in 1989 when the CTN was established include: involvement in compassionate access trials, the inclusion and education of the HIV/AIDS community, information and referral services, ethics reviews and the need to support physicians in their treatment decisions. The CTN has taken steps to address each of these issues. As well, the CTN has attempted to be more proactive in developing clinical trials. The associateship program, for example, addressed the insufficient pool of qualified HIV clinical trialists available in Canada to direct studies. Workshops and the Letter of

Intent process were designed to provide alternatives to industry-initiated trials and to try to respond some of the research gaps.

There is a general consensus among those interviewed that a clinical trials network continues to be needed in Canada and that the CTN makes a relevant contribution to the broader Canadian and international research effort through the facilitation of clinical trials. These trials, together with other HIV/AIDS research have contributed to the development of effective new drugs therapies (e.g., 3TC, protease inhibitors) and to tests of the efficacy and toxicity of new combination therapies.

Despite the recent success of new drug therapies, key informants strongly believe that the CTN has a continuing role to play in the development of drug treatments. While protease inhibitors and combination therapies have been successful in reducing the amount of detectable HIV in the blood, the effectiveness of these drugs in the longer-term is unknown. Researchers do not consider the current therapies to be a cure. Past treatment approaches have shown that drug effectiveness can wane over time as the virus becomes resistant. Moreover, the drugs have been shown to be less effective in patients with established infections and some individuals do not respond to the therapies at all. There is, therefore, a perceived need to continue research into effective treatments and vaccines.

There is also a need, according to respondents, for greater attention in clinical trials to management studies related to existing drug therapies — such as refinements to required dosage strengths, combination effects and frequency of medication. As the disease moves into more marginalized populations, methods must be found to administer drugs in a more simplified way. The complicated daily regimens which characterize current drug therapies place a large burden on patients like IDUs who do not have the required stability in their eating and living habits to comply with these complicated regimens.

Finally, there is a perceived need for government-sponsored funding for HIV/AIDS research in general. HIV/AIDS research is not considered to be mainstream research with access to multiple private and public research resources. Continued support for organizations such as the CTN is viewed by key informants as maintaining high quality HIV/AIDS research in Canada that would not have access to funding through other sources.

Our survey of people living with HIV/AIDS also confirms that there is considerable interest in clinical trials, though this demand is not currently met by the level of clinical trial activity in Canada. The majority of respondents (73 per cent) indicated that they have wanted to be in a research study with new treatments, with 40 per cent saying they have been and 33 per cent indicating they have not. Differences were found when responses were broken down according to whether respondents had been diagnosed with HIV prior to 1993 or as of 1993. Fifty-one per cent of those diagnosed prior to 1993 have participated in a research study compared to 23 per cent of those diagnosed as of 1993. Also, 36 per cent of those diagnosed as of 1993 indicated never having wanted to participate compared to 17 per cent of those diagnosed prior to 1993.

For those respondents either having participated in a research study or wanting to participate, it is their perception that it is not particularly easy to get into a research study with new treatments. Twenty-three per cent feel it is not too hard, with 21 per cent thinking it is quite hard and 14 per cent feeling it is very hard. Only 10 per cent thought it was very easy and 13 per cent did not know. There were no statistically significant differences when responses were categorized according to when they had been diagnosed with HIV.

Impacts

The key objectives of the CTN are to seek out opportunities or facilitate the conduct of clinical trials and to foster communication among the appropriate stakeholders. In terms of the former, it is difficult to establish with absolute certainty the number of clinical trials that would have been conducted in Canada without the CTN. Certainly there are clinical trials that are currently conducted in Canada without the approval of the CTN. In fact, according to the June 1996 *Directory of HIV Trials in Canada* there were 53 open clinical trials. Of these, the CTN was listed as a trial co-sponsor in seven trials and an additional 17 trials were affiliated with the CTN (i.e., had a CTN protocol number). Study sponsors may choose not to affiliate themselves with the CTN for a number of reasons. For some pharmaceutical companies, the CTN is not perceived to provide any "value-added" to their clinical trials. Companies have fully developed research services and do not have a requirement for the management services offered by the CTN. The CTN is also perceived by some sponsors to add a layer of bureaucracy to the clinical trials process (e.g., submission, review and approval processes) potentially causing delays and increasing costs.

Key informants, however, generally believed that the organization had had a significant positive impact in attracting clinical trials to Canada. By providing pharmaceutical companies with access to a variety of services (e.g., protocol development, data management) and to an established infrastructure of investigators and sites, the CTN is able to attract a greater number of trials to Canada.

There are also several noteworthy studies which certainly would *not* have happened without the CTN. The "MAC study" is an example of a "Network-driven" trial where the CTN provided comprehensive services from protocol design to study coordination, data management, and finally reporting. Over 200 patients were enroled in 24 sites across Canada. The study, designed to test the effectiveness of two types of drug regimens in treating patients with MAC bacteraemia, is viewed as a significant contribution in clinical management of HIV patients. The recent collaborative study with the CPCRA, given the scope of the project, also would not have happened without an established, credible clinical trials infrastructure.

For those clinical trials which have been conducted through the CTN, through negotiations with pharmaceutical companies, the CTN has tried to encourage the conduct of clinical trials in smaller and remote centres in all regions (though this is limited to a large extent by a lack of leverage with sponsors who are unwilling to absorb the extra costs associated with expanding the number of sites for trials). According to key informants, in the absence of the CTN, clinical trials in Canada would be concentrated in the larger centres of Vancouver, Toronto and Montreal.

Interviews with provincial stakeholders confirm the difficulty of extending trials to multiple centres. The provincial representatives noted that while the CTN has been useful and effective for some provinces, it has been largely irrelevant to others, particularly in smaller provinces with relatively fewer HIV/AIDS cases.

For patients, participation in clinical trials and the advances in research resulting from clinical trials have significant benefits. Volunteers in clinical trials have been allowed access to new drug therapies which were not available for release under other circumstances. The development of new drug therapies, to which research such as that conducted by the CTN has contributed, has reduced morbidity and mortality among HIV/AIDS patients and also improved quality of life.

In our survey of stakeholder groups, sixty per cent believed clinical trials had produced benefits for people living with HIV/AIDS. Four per cent believed clinical trials had not produced any benefits and 18 per cent rated the benefit as moderate. Satisfaction with the CTN among these groups is quite high, though there is a substantial proportion of respondents (27 per cent) who did not respond or responded "don't know" to this question (this proportion was higher [at 50 per cent] among professional associations). Forty-two per cent of respondents reported being satisfied with the activities of the CTN, 25 per cent were moderately satisfied and six per cent were not satisfied.

Our survey of people in Canada living with HIV/AIDS sheds further light on the impacts of the CTN. Fifty-eight per cent of respondents had heard of the Clinical Trials Network and 26 per cent of those have participated in its activities. Of the 30 respondents that had participated in its activities, 43 per cent feel that it had helped some and 40 per cent feel it helped a lot. Seven per cent feel it was almost not at all helpful and seven per cent feel it was not at all helpful. Differences were noted when responses were broken down according to whether respondents had been diagnosed prior to 1993 or as of 1993. Sixty-four per cent of respondents who had been diagnosed prior to 1993 had heard of CTN compared to 48 per cent of those diagnosed as of 1993. In terms of use and helpfulness of the information, there were no statistically significant differences.

The second objective of the CTN is to foster communications among appropriate stakeholders. As mentioned in the previous sections, the CTN has been active in enhancing communications among researchers, clinicians and the community in the field of clinical trials. The CTN, through its clinical trials, has contributed to the development of a cadre of skilled and recognized HIV clinical trialists across Canada (according to the CTN, virtually all investigators in the HIV/AIDS field are linked to the CTN). These physicians gain an early familiarity with HIV/AIDS drug therapies and their side effects and are able to provide better care and treatment for their patients. Funding of three associateships each year encourages new investigators to enter and be trained in HIV clinical trials. The CTN has made efforts to ensure broader knowledge and understanding of the results of clinical trials through a variety of distribution strategies.

Cost-Effectiveness

Some stakeholders and key informants questioned the relatively high cost of the CTN and its accountability for resources expended at the National Centre. Some suggested that a closer relationship with the US clinical trials network could have significantly reduced the costs associated with running the CTN.

CTN evidence on the cost-effectiveness is derived primarily from two sources: multiplier effects or leveraging of funds from third party sources; and efficiency comparisons with a similar clinical trials network in the United States. With respect to the former, the bulk of funding leveraged by the CTN is from pharmaceutical companies ($11 million) for drug costs and trial operating expenses. Provinces also contribute about $3.5 million annually for lab tests, office space and salaries (Exhibit 5). The true multiplier effect of the NAS-II investment in the CTN is likely somewhat lower than the six-fold leveraging indicated in the table and is dependent on the extent to which clinical trials approved by the organization are incremental (i.e., would not have happened in the absence of the CTN). Because this is unknown, it is difficult to provide an accurate accounting of the true multiplier effect.

EXHIBIT 5
Clinical Trials Funding

Source	Amount (annual)
Federal government (NAS-II)	$2.9 million
Provincial government (payment of rent, university salaries and lab costs)	$3.5 million
Pharmaceutical company (drug costs and operating expenses for trials)	$12.1 million ($4.6 million in drug costs)[1]
Total	$18.5 million

1. About one-half of the leveraged drug costs from pharmaceutical companies comes from two compassionate access trials for d4t (C048) and 3TC (C058).

The efficiency indicators are based on comparisons between the CTN and the AIDS Clinical Trials Group located in the United States. The data which have been compiled by the CTN indicate a high level of efficiency compared to the ACTG in terms of per capita funding for clinical trials. For example, while the CTN spent one per cent of the US budget over a six year period, it enroled about ten per cent of the number of volunteers (an efficiency factor of about 12 times). Some of the efficiencies are accounted for in terms of differences between the Canadian and American health care systems — the Canadian system being more efficient and some of the costs of the CTN for investigator salaries and overhead being absorbed under general health care budgets. While it is difficult to do a strict comparison, at least half of the demonstrated efficiency could be attributed to the CTN's multiplier effect (e.g., leveraging from pharmaceutical companies) and efficiencies in the organization according to key informants.

Project Specific Issues

One of the issues which the CTN has raised in this study and in other contexts is the limited mandate and lack of funding for the CTN to develop and conduct its own clinical trials. Currently, the CTN may only *facilitate* clinical trials, with funding of these trials being absorbed primarily by industry and, to a much lesser extent, by granting agencies. According to CTN key informants, expanding their capacity to conduct clinical trials autonomously would free the CTN from the research agenda that is now driven primarily by the pharmaceutical companies. This industry-sponsored research has, to date, been focused on testing the efficacy of new drug therapies developed by companies. There are, however, many potentially fruitful lines of inquiry which do not capture the interest of the industry. These include, for example, management studies which focus on testing dosage levels and timing of intervention. It is also difficult to attract funding for clinical trials of alternative non-pharmacological therapies (e.g., vitamin therapies which cannot be patented) and complementary therapies (e.g., therapies used to reduce side effects, increase absorption or improve quality of life). Finally, marginalized groups such as IDUs are often shunned by corporate sponsors for participation in clinical trials because they are perceived to be unreliable. As a consequence, however, these types of groups are systematically excluded from access to investigative drugs.

The reason that has been cited to the CTN for not funding autonomous trials is conflict of interest — i.e., the government cannot be responsible for both testing and approval of drugs. There are, in fact, international precedents for the conduct of independent research by government funded clinical trials networks, however. The ACTG in the United States, for example, is funded to conduct autonomous trials. Counterpart organizations in the UK, France, and Australia also share this mandate.

A second issue according to key informants, is the difficulty of the CTN in planning clinical trials based on the five-year funding horizon. Clinical trials are expensive and are often conducted over a long time period (e.g., two to three years). According to key informants, the five-year funding period severely limits the ability of the CTN to plan and facilitate clinical trials.

Finally, a third issue is the funding of the CTN. Since its inception, CTN has been asked by Health Canada to search for other sources of funding to supplement the contributions of the federal government. In response, *CTN Services* was formed which is intended to offer services on a contract basis to pharmaceutical companies (e.g., data analysis, ethics review service). This effort is in the beginning stages only, with a business plan and market situation analysis having been prepared. Key informants from the CTN expressed some doubt about the ultimate success of these efforts, however, to make a substantial contribution to the overall cost of the CTN infrastructure.

Summary

Continued Relevance

It is in the opinion of key informants involved directly with the CTN that the clinical trials facilitated by the organization have contributed to the broader Canadian and international research effort to develop new treatment therapies. These trials and other research have contributed to the development of effective new drugs (e.g., 3TC, protease inhibitors) and continue to test the efficacy and toxicity of new combination therapies.

The mandate of the CTN has evolved since its inception in 1989, and the organization has also had to overcome some misconceptions about its objectives. In addition to clinical trials, the CTN is involved in information dissemination, education and development, and ethical reviews.

Despite the recent success of new drug therapies, key informants strongly believe that the CTN has a continuing role to play in the development of drug therapies. Existing treatments, while improving mortality and morbidity rates among HIV/AIDS patients, do not represent a cure. There is a need for continued research efforts into effective treatments and vaccines, as well as attention to "management" studies to improve information on issues such as dosage strength and timing of interventions.

The management and organization of the CTN has presented challenges. Regional tensions around communications and financial issues, in particular, have surfaced. Accountability concerns have also been voiced by stakeholders outside of the organization.

Effectiveness/Success

The key impacts of the CTN, as noted by key informants, include:

- ☐ increased the initiation of clinical trials in Canada. It is difficult to establish with certainty the number of clinical trials that would have been in Canada without the CTN. Indeed, there is significant clinical trial activity that is carried out outside of the auspices of the CTN. Key informants believe that by providing pharmaceutical companies with access to a variety of CTN services (e.g., scientific review, community review) and access to an established infrastructure of investigators and patients, the CTN is able to attract a greater number of trials to Canada. This is particularly true for large scale, multi-site trials such as the recent collaboration with the CPCRA. For many companies, however, the services offered by the CTN are not necessary to their operation and simply represents an unwanted layer of bureaucracy.

- ☐ for patients, participation in clinical trials has allowed them access to new drug therapies. These drugs have reduced morbidity and mortality and improved the quality of life of HIV/AIDS patients.

- ☐ through negotiations with pharmaceutical companies, the CTN has tried to encourage the conduct of clinical trials in smaller and remote centres in all regions (in all, over 30 centres have participated in CTN-affiliated trials). The CTN, however, lacks significant leverage with study sponsors who often resist the additional expense of including multiple sites. According to key informants, in the absence of the CTN, clinical trials in Canada would be concentrated in the larger centres of Vancouver, Toronto and Montreal.

- ☐ through communications and education activities, the CTN has contributed to the development of a cadre of skilled and recognized HIV clinical trialists across Canada. These physicians gain an early familiarity with HIV/AIDS drug therapies and their side effects and are able to provide better care and treatment for their patients. Funding of three associateships each year encourages new investigators to enter and be trained in HIV clinical trials.

- ☐ international collaboration and contribution. A significant portion of CTN trials have involved international collaboration (defined in terms of the location of the study sponsor or participation in multi-national trials). Research that has been facilitated by the CTN has resulted in numerous publications and conference presentations in Canada and abroad.

- ☐ information dissemination. The CTN has made efforts to ensure broader knowledge and understanding of the results of clinical trials. The CTN distributes information through regular workshops, the CTN web site, bi-monthly newsletters, clinical trials information kits for physicians and regular mailings. The CTN also provides trial result information to CATIE which is made available to the HIV/AIDS community and health professionals through the AIDS Treatment Information Network.

Cost-Effectiveness

Evidence on the cost-effectiveness of CTN is derived primarily from two sources: multiplier effects or leveraging of funds from third party sources; and efficiency comparisons with a similar clinical trials network in the United States. In terms of multiplier effects, the CTN figures show leveraging of six times the annual $2.9 million in federal funding, though this figure is likely somewhat lower if one excludes trials which would have been conducted in Canada even in the absence of the CTN. The CTN can also be shown to be relatively efficient when compared to its counterpart in the US, though some of this efficiency premium is due to differences between the health care systems of Canada and the United States.

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 7:
National AIDS Clearinghouse Case Study

September 2, 1997

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 7:
The National AIDS Clearinghouse Case Study

The National AIDS Clearinghouse is located within the Canadian Public Health Association (CPHA). CPHA is an independent, national, not-for-profit, voluntary association which represents public health in Canada. CPHA's mission is:

> *to constitute a special national resource in Canada that advocates for the improvement and maintenance of personal and community health according to the public health principles of disease prevention, health promotion and protection and healthy public policy.* (1996 Canadian Public Health Association's Executive Director's Report)

Based on this mission, the CPHA has set for itself the following goals:

- *to act in partnership with a range of disciplines including health, environment, agriculture, transportation, other health-oriented groups and individuals in developing and expressing a public health viewpoint on personal and community health issues;*
- *to provide an effective liaison and partnership with CPHA's Provincial/Territorial Branches/Associations;*
- *to provide an effective liaison and network both nationally and internationally in collaboration with various disciplines, agencies and organizations;*
- *to encourage and facilitate measures for disease prevention, health promotion and protection and healthy public policy;*

- ☐ *to initiate, encourage and participate in research directed at the fields of disease prevention, health promotion and protection and healthy public policy;*
- ☐ *to design, develop and implement public health policies, programs and activities;*
- ☐ *to facilitate the development of public health goals for Canada;*
- ☐ *to identify public health issues and advocate for policy change; and*
- ☐ *to identify literacy as a major factor in achieving equitable access to health services.*

Amongst CPHA activities are six international programs and seven national programs including the national CPHA AIDS Program. The CPHA AIDS Program includes the National AIDS Clearinghouse. The Clearinghouse Manager reports to the Director of the AIDS Program who has overall responsibility for the Program. The funding for the CPHA AIDS Program is provided by Health Canada through Phase II of the National AIDS Strategy and is for a five year term (April 1993 - March 1998). The funding for 1996/97 can be broken down accordingly: $641,000 for the Program and $784,000 for the Clearinghouse.

For the delivery of the AIDS Program, including the National AIDS Clearinghouse, CPHA has partnered with many organizations, including: HIV/AIDS Policy, Coordination and Programs Division of Health Canada, Canadian Haemophilia Society (CHS) and the Canadian AIDS Society (CAS). These three partners sit on the CPHA AIDS Advisory Committee (Health Canada sits as an observer). Membership on the Advisory Committee is determined by the CPHA Board of Directors and the Chair of the Committee reports to the Board. On a formal basis, these partners, through the Committee, oversee general policy and programs, review workplans and progress reports and provide advice. Informally, the Clearinghouse and the AIDS Program have daily contact with the CHS and CAS. CPHA's relationship with these partners is perceived by those interviewed to be strong and very effective.

Of interest to this study is the National AIDS Clearinghouse which will be the focus of the remainder of this case study report.

Background and Context

CPHA first received funding from Health Canada in 1984 to establish the AIDS Program which was to focus on education and training. The CPHA AIDS Program also included the National AIDS Clearinghouse. From 1987 to 1991, there was also a Federal Centre for AIDS. Once this Centre was disbanded in 1991, the AIDS education resources were transferred to CPHA. The AIDS Program and the National AIDS Clearinghouse each have their own contribution agreement with Health Canada. Although Health Canada regards them separately, both contribution agreements are managed as part of the AIDS Program. The National AIDS Clearinghouse's mandate is:

> *to collect and circulate a comprehensive collection of AIDS educational materials across Canada, and to act as the central Canadian documentation centre on AIDS education materials.* (1997-98 Detailed Workplan)

Based on this mandate, the Clearinghouse has four major objectives (1997-98 Detailed Workplan, p. 2):

1) to provide a source of educational materials on HIV/AIDS to educators across Canada;
2) to strengthen collaboration among HIV/AIDS resource centres and other partners;
3) to promote Clearinghouse services and expertise to AIDS educators and to all Canadians; and
4) to identify trends and assess public demand for the development of HIV/AIDS educational materials.

The Clearinghouse has a broad range of resources in both its distribution and reference collections, covering education, awareness, prevention and treatment[1]. In the current distribution collection, there are approximately 400 items which have been supplied by 81 organizations. These organizations produce resources (e.g., pamphlets) which are then given to the Clearinghouse for distribution. In addition to distributing an organization's product when it is requested, the Clearinghouse can also do a proactive mailout of the product for the organization. Examples of the types of resources available for distribution include pamphlets, brochures, catalogues and guides.

The reference collection currently consists of 14,800 documents, from international as well as Canadian sources, including an extensive collection of over 200 periodicals. The size of this reference collection makes the Clearinghouse the largest AIDS resource centre in Canada. While two thirds of the resources are produced by Canadian organizations, resources are available in 102 different languages and from more than 80 countries. Access to this collection can be gained via an interlibrary loan. Examples of the types of resources that can be taken out on loan include reports, videos, pamphlets and journals. Staff at the Clearinghouse will also undertake complex searches of the Clearinghouse collection and commercial databases and will produce bibliographies on detailed topics for clients. Requests for information or resources from either collection can be made over the telephone, by mail, fax or e-mail. In the first three quarters of 1996-97, they had received 45,000 requests.

Needs and Implementation

The primary need being addressed by the Clearinghouse is the need of individuals involved in educating or raising awareness of AIDS to have access to educational resources and to be able to obtain what they need through one telephone call/request (i.e., one-stop shopping). The philosophy behind the Clearinghouse is to meet the education and awareness needs of front-line AIDS educators.

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[1] The Clearinghouse has only a limited amount of information on treatment due to the activities of the Community AIDS Treatment Information Exchange (CATIE).

Respondents believe the level of awareness of the Clearinghouse to be good. This view is supported by a 1994 study by J. Phillip Nicholson Policy and Management Consultants Inc. which showed that 70 per cent of the study's respondents (i.e., "selected current and potential clients") were aware of the Clearinghouse. Respondents of this current evaluation, however, did note that awareness of the Clearinghouse is not universal. The two main reasons offered for this were: 1) there is a huge turnover in the AIDS community; and 2) more communities and people are getting involved (e.g., aboriginal and ethno-cultural communities, private sector). One respondent also noted that while people may be aware of the Clearinghouse, they may not be aware of all its services, such as the reference collection. For example, according to the results of an HIV Prevention: Public Health Participation Questionnaire recently undertaken by CPHA, just over half of respondents (58 per cent) were aware that the Clearinghouse conducts bibliographic searches. Attending regional conferences was cited as being an important way of raising awareness of the Clearinghouse and its services, as was the proactive policy to mail out information to areas where it is not known.

In the present evaluation, 77 per cent of the stakeholders surveyed were aware of the Clearinghouse and its services, with the awareness rate being somewhat higher among community organizations (82 per cent). It is important to note, however, that part of the sampling frame was obtained from lists of groups that have contacted the Clearinghouse. Thus, this awareness rate may be somewhat overstated. In Ekos' survey of people living with HIV/AIDS, 48 per cent of respondents indicated being aware of the Clearinghouse.

The perception of those at the Clearinghouse is that their resources (i.e., both the distribution collection and the reference collection) are accessible to all target groups and all regions. For example, videos and other resources have been loaned out to individuals and organizations in remote areas. The general public can also access the Clearinghouse's reference collection via an interlibrary loan. There are 39 types of clients requesting information from the Clearinghouse. The distribution of resources across these client types in 1996 is presented in Table 1. As the table illustrates, by far the majority of resources were distributed to community AIDS organizations. Public health units and various associations have also utilized a significant amount of the Clearinghouse's resources.

Table 2 presents the distribution of the 12 most popular items across provinces/territories, as well as to the United States and other countries for 1996. As the table indicates, the majority of the 12 items were distributed to Ontario followed by Quebec and then British Columbia. In Canada, Prince Edward Island and the Yukon received the fewest items.

Respondents were in general agreement that there is no one product that is key to their mandate. There are, however, "hot items" some of which reflect the issues of the day. Some of the more popular items include the basic facts about AIDS, resources on women and HIV/AIDS and the five module set which provides information on the treatment and care for people living with AIDS. While not all items are as equally popular, the perception of one respondent is that not many of them are slow movers. If a product is not moving well, the publisher is informed so that an overabundance of copies are not produced.

TABLE 1
Distribution by Client Types in 1996

Client Type	Resources Distributed
Community AIDS Organizations	422,071
Public Health Units	171,800
Associations	123,439
Provincial Governments	66,860
CLSCs	59,193
Universities and Colleges	54,838
General Public	53,388
Hospitals	52,130
First Nations Groups	48,959
Social Service Agencies	32,786
Family Physicians	32,734
Municipal Governments	29,430
Federal Government	28,751
Schools	28,158
Private Sector	26,051
Funding Agencies	19,318
Housing	17,424
Youth Agencies	12,354
Correctional	10,281
Research Agencies	7,838
Family Planning Groups	6,336
Child Care	6,276
Home Care	5,361
Needle Exchange	5,333
Women's Groups	4,965
Ethno-cultural Groups	3,833
Students	3,680
Libraries	3,212

Client Type	Resources Distributed
Religious Agencies	2,818
Voluntary Agencies	2,638
National Government	2,550
State Governments	1,111
Art Groups	507
Undefined Client Type	310
Trade Union	305
Police	263
Territorial Governments	216
International Clearinghouse Partner	91
Media*	18
TOTAL	**1,347,626**

Source: Data extracted from the Clearinghouse distribution database.

* Media contact is through the CPHA Director of Public Affairs and Communications, the Director of the AIDS Program and the Clearinghouse.

TABLE 2
Distribution of the 12 Most Popular Items by Region

Region	Resources Distributed													
	AAW Materials	Basic Facts	Women and AIDS	We Need to Know	Caring Safely	Discrimination and HIV	Learning about AIDS	Module 4	Counselling Guidelines	Module 2	Module 3	Module 1	TOTAL	% of Total
Alt.	42,347	11,092	12,852	2,643	4,648	1,505	2,158	378	3,123	542	549	478	82,313	8.0%
B.C.	40,030	13,096	12,047	8,993	5,429	2,071	1,135	1,600	1,910	1,641	1,839	1,538	91,329	8.8%
Man.	17,457	4,662	4,169	2,493	3,721	893	1,092	57	80	314	222	364	35,544	3.4%
NB.	14,469	6,139	4,525	2,072	1,122	1,214	775	65	72	188	384	119	31,124	3.0%
Nfld.	25,338	15,315	3,439	1,932	408	273	1,749	136	134	233	225	206	49,388	4.8%
N.S.	43,538	15,261	7,469	3,805	6,148	2,146	630	595	435	170	315	202	80,714	7.8%
NWT	3,081	1,837	1,126	370	168	211	0	1	10	11	26	12	6,853	0.7%
Ont.	134,484	119,561	42,403	52,278	14,459	13,438	4,640	3,648	4,113	3,679	3,876	3,081	399,660	38.6%
P.E.I.	844	271	92	1,321	120	1	457	2	52	4	12	4	3,180	0.3%
Que.	64,714	41,958	32,883	24,147	9,385	12,376	1,420	3,712	1,364	1,981	3,331	3,461	200,732	19.4%
Sask.	22,240	7,555	2,385	678	3,462	384	842	354	555	366	300	447	39,568	3.8%
Yukon	1,091	1,002	0	400	402	200	1	0	50	104	61	53	3,364	0.3%
U.S.	39	2,028	2,004	998	706	163	131	2,047	110	61	52	45	8,384	0.8%
Other	6	766	627	377	27	29	13	52	21	60	57	19	2,054	0.2%
TOTAL	409,678	240,543	126,021	102,507	50,203	34,904	15,043	12,647	12,029	9,354	11,229	10,049	1,034,207	100%

Source: Data extracted from the Clearinghouse distribution database.

Interview respondents cited a number of ways in which needs were identified. The most common ways were through Health Canada, the CPHA Advisory Committee, AIDS organizations, requests for resources, and from feedback received at conferences and workshops. In terms of Health Canada, the Clearinghouse's workplan which identifies the Clearinghouse's objectives and goals is reviewed by Health Canada and epidemiological data produced by the Laboratory Centre for Disease Control (LCDC) helps the Clearinghouse to identify trends and changes in the target group. Surveys and polls such as the study conducted by J. Phillip Nicholson Policy and Management Consultants Inc. in 1994, have also been used to identify needs. The J. Phillip Nicholson study, which was a needs assessment of the Clearinghouse, identified throughout the report various information needs (e.g., information about HIV/AIDS related specifically to aboriginal peoples).

Currently there is no detailed marketing plan, although marketing activities are part of the annual workplan. According to one respondent, the Clearinghouse reacts to the demands of its clients. The staff at the Clearinghouse knows who their clients are and have built up a lengthy list of contacts across the country. Additionally, the Clearinghouse is the Secretariat for CANNET (a network of AIDS resource centres), as well as for the Global AIDS Resource Network (GAIN). Considerable promotion also happens through conferences. Overall, respondents did not perceive the lack of a detailed marketing plan as being a problem. However, it was noted by one respondent that, with the implementation of the cost recovery program in the Clearinghouse (to be discussed in more detail later), the necessity for a detailed marketing plan has become more pronounced.

The Clearinghouse has grown exponentially over the past few years. As of 1995-96, the Clearinghouse handles several million items and approximately 60,000 requests per year. Table 3 provides an overview of the increasing levels of demand and number of items shipped since 1989-90 as detailed in the 1996-97 workplan for the Clearinghouse.

TABLE 3
National AIDS Clearinghouse Statistics 1989-1996

	1989-90	1990-91	1991-92	1992-93	1993-94	1994-95	1995-96*	TOTAL
Requests	4,563	11,346	25.530	21,955	30,315	42,000	46,000	181,709
New titles	30	195	85	83	110	136	167	806
Total titles	30	225	310	393	503	639	806	806
Items	925,346	2,309,939	3,000,000	1,922,816	1,304,000	1,450,000	1,300,000	12,212,101

Source: Data extracted from the Clearinghouse distribution database.

* These numbers reflect only the first three quarters of 1995-96.

As Table 3 shows, over the past seven years, the number of titles carried by the Clearinghouse has increased to 806 with the number of requests continually increasing each year. While the total number of items dropped off after peaking in 1991-92, the last couple of years have shown a steady increase.

The resources carried by the Clearinghouse are considered by key informants to be uniquely comprehensive, including a great deal of "grey" literature (i.e., items difficult to find as they are not available from a commercial venue, such as pamphlets, reports that have a very limited distribution or reports from small organizations). Additionally, efforts are made to keep abreast of new information, including international sources, and to keep the databases current.

As demand on the Clearinghouse has increased, so has number of the Clearinghouse staff: from three in 1989 to the seven who are currently employed. While there are specific roles and responsibilities for each position as outlined in the Policy and Procedures manual, the need for staff to be able to flow from one activity to another and work as a team to ensure the efficient and effective delivery of services was noted by one respondent. While the staff has increased in size, this increase is considered minimal compared to the increase in the demand for services.

In addition to the increase in staff, other changes in resources have occurred. Since 1989, a computerized database has been used which allows the Clearinghouse to keep track of clients and to search clients' requests should a follow-up be necessary. The reference and distribution collections have also been put into a database. This has enabled the Clearinghouse to record when an item is due back to the reference collection and who is next in line for that item. Finally, the Clearinghouse is now on the World Wide Web. Respondents also indicated that they expect to expand and enhance this service.

Given the increase in demand, it is not surprising that the client base of the Clearinghouse has also broadened. While it is the perception of those interviewed that AIDS Service Organizations (ASOs) and the public health community have been and always will be the two main organizations in terms of demand, it was noted that there are a number of new clients (e.g., schools, women's groups, aboriginal groups, IDUs, corrections, organizations at the grass roots level) (see Table 1).

Respondents did not feel that the activities of the Clearinghouse duplicated those of other organizations. It was noted that there is a clause in the contribution agreements between Health Canada and AIDS organizations stating that all products must be distributed through the Clearinghouse. It was further indicated that the Clearinghouse complements the activities of others by working in collaboration with them (e.g., schools, libraries) and, through its role as Secretariat of CANNET, provides smaller resource centres with support by acting as a mentor.

The infrastructure of the Clearinghouse is perceived by respondents to be adequate in terms of organization, training and support. A new computer system will be required and this will mean either retraining staff or hiring people with a new skill set. Being located within CPHA was seen by respondents to be particularly beneficial because of the interaction and synergy with other programs, as well as the support structure. These benefits were also noted in the J. Phillip Nicholson study. According to this study, there are no significant problems associated with having the

Clearinghouse located within CPHA, with the Clearinghouse actually benefitting from having access to shared facilities and services, as well as having back-up support for reception and administrative functions.

Given these benefits, it is the perception of respondents that the Clearinghouse is best located within CPHA as part of an integrated AIDS Program. One caveat of having the Clearinghouse located within CPHA, as noted in the J. Phillip Nicholson study, is that there is a blurred distinction between the CPHA in general and the Clearinghouse. According to this study, this lack of distinct identity of the Clearinghouse may be the reason why a relatively large proportion of potential users are not aware of the Clearinghouse.

Management of the Clearinghouse have made efforts to make the Clearinghouse as cost-effective as possible, including reducing administrative and overhead costs. In January 1996, the CPHA AIDS Program held a one-day workshop with key CPHA staff to examine 40 possible options and initiatives of a cost recovery/savings plan. During the workshop, options were evaluated according to ten criteria which covered five broad areas: cost savings/cost avoidance; charging/cost recovery; new products and services/alternative delivery; joint ventures/project funding; and sponsorship. In February 1996, a similar workshop was held with the CPHA AIDS Program Advisory Committee. Based on the outcomes of these workshops, a cost recovery/savings plan was developed.(*Canadian Health Association National AIDS Clearinghouse: Cost Recovery, Cost Savings and Income Generation Plan,* February, 1996).

To date, two aspects of the plan have been implemented. While the Clearinghouse makes one copy of everything available to clients free of charge, clients are now requested to pay for the shipping costs of anything above that. For example, the cost to ship up to 10 copies of a pamphlet is $3.00 in Canada, $5.00 to the US and $10.00 overseas. This should result in substantive cost recovery as 22 per cent ($172,400) of the 1996/97 budget was spent on postage and courier costs. The

Clearinghouse requires payment for shipping costs before the request is sent. If the client is not using a credit card or a purchase order number, they are sent a "fax-back" form (or a letter if overseas) detailing their order which the client can then fax back to the Clearinghouse with details as to method of payment.

All respondents have noticed that the shipping charges have resulted in a decline in demand for Clearinghouse resources. Although some feel that this is a "blip" and that demand will come back on track once clients get used to it, others expressed concern that some clients would not be able to afford the costs at any time. In fact, one of the organizations studied as part of another component of this study indicated that they would not use the Clearinghouse in the future because it was too expensive. This would, in essence, reduce its accessibility for some clients. The Clearinghouse has also started charging for some bibliographic searches.

Other measures have been undertaken to make the Clearinghouse more cost-effective. The inventory in its warehouse has been closely examined. Suppliers of items that were not moving or were out-of-date were notified by letter that, except for a small number to be kept on hand, these items would be recycled unless they wanted the materials returned to them. In the letter, suppliers were informed of the title of the item, date of publication, current quantity and the number being kept. Some items, for example those in multiple languages, were offered to organizations or embassies before being recycled. This has resulted in a reduction in the space needed in the warehouse and, consequently, the cost. The inventory at the warehouse is now reviewed by the Clearinghouse manager on a regular basis to determine whether other resources can either be returned to suppliers or recycled.

Last December, a pilot was run to determine which method of shipping was the least expensive: 4th Class or piece kilo. It was determined that piece kilo was the least expensive and was adopted as the Clearinghouse's method of shipment. The Clearinghouse also has a special postal rate. Additionally, the Clearinghouse is encouraging people to coordinate their requests (e.g., individuals from different branches within Health Canada) and to look closely at their needs to ensure they do not over order. Finally, management put out a tender for computer maintenance and are now receiving maintenance at a less expensive cost. It is believed by those interviewed that these steps have made the Clearinghouse leaner and more effective.

For 1996-97, CPHA intends to investigate other cost-effective options that were identified as having the greatest possible benefits (*Canadian Health Association National AIDS Clearinghouse: cost recovery, cost savings and income generation plan*, February, 1996). These include, for example:

- ☐ charging suppliers for handling materials — proactive distribution;
- ☐ sales of printing films for reprints by others;
- ☐ develop service as printing broker;
- ☐ solicit commercial advertising;
- ☐ cooperation with CTN (Clinical Trials Network) and CATIE (Community AIDS Treatment Information Exchange);
- ☐ active membership with CANNET; and
- ☐ Internet publishing.

It is also hoped that in the near future the Clearinghouse will be able to expand its services on the Internet and become a virtual Clearinghouse. The expansion of the web site, which would include the reference and distribution collections, is perceived by respondents as another cost-effective measure (e.g., reduce postage, people could do their own bibliographic searches). It is also believed by one respondent that once the services on the web site have been expanded, it will transform the way the Clearinghouse does business.

Impact on Access

Overall, respondents felt the Clearinghouse had improved Canadians' access to information about HIV/AIDS. It is the opinion of respondents that the information provided is reliable and timely. For example, the fact sheets are checked periodically to ensure they are current. In terms of timeliness, new publications received by the Clearinghouse are identified in the *Canadian AIDS News* which is published by CPHA four times a year. The Clearinghouse also publishes a catalogue of its resources once or twice a year, within which all new titles are highlighted. All resources are considered by respondents to be educational and informational. It was noted, however, that it is difficult to know the extent to which they are effective as this depends on the target group and the intended use.

It is also the perception of respondents that the Clearinghouse is accessible to clients. One respondent noted that the phone trunk system which they have in place makes it easy for clients to reach the Clearinghouse (i.e., when a client calls, if the first line is busy it automatically shifts to the next available line). Additionally, clients can e-mail or fax their requests. Clients can now also leave a message after hours on voice-mail. Other efforts that have been made to increase the accessibility of the Clearinghouse include: increased attendance at regional conferences; and the "Clearinghouse in a Suitcase". The "Clearinghouse in a Suitcase" is a table top display that explains what the Clearinghouse is, what they have and how they can be reached. Samples of some of their resources are also provided. This "suitcase" is available upon request at no cost. The Clearinghouse also works closely with the CPHA AIDS Program, national partners and Health Canada in identifying gaps based on what the Clearinghouse hears and on requests for information.

Respondents were pleased with their partnerships, believing them to be very effective. Through their partnerships with organizations such as the AIDS service organizations, schools, public health units and national partners, they have been able to support many organizations. In some instances, partnerships around conferences have enabled the Clearinghouse to stretch dollars. For example, one time the Clearinghouse was able to arrange for a free booth because it provided a service to the conference. At other times it has been able to negotiate airfare and expenses.

The Clearinghouse's partnerships and relations with CATIE and CAS are also perceived by respondents as being effective. The fact that the Clearinghouse manager sits on CATIE's National Advisory Committee is seen as one way of avoiding duplication of services. CAS and the Clearinghouse have daily contact on an informal basis as well as around specific functions such as the AIDS Awareness Week, in which the Clearinghouse has provided background material and is in charge of distribution. The Clearinghouse also signs off responsibility for materials produced. The Clearinghouse's role on CANNET's Advisory Committee is also seen to be an effective partnership by respondents.

Impacts on Clients

There was consensus amongst respondents that the Clearinghouse has had a positive impact on its clients. The primary use of the information from the Clearinghouse is believed to be to educate others about HIV/AIDS. It is also believed that in some cases decision-makers may use their information to make decisions about program interventions and policies even if it is just as background material. Respondents felt that, through their referrals, the Clearinghouse enables clients to link to other resources and to other resource centres. Finally, respondents were in agreement that the information it provides is a source of empowerment for its clients.

Some of the respondents did acknowledge that information from the Clearinghouse could cause some confusion. One respondent commented that the mere volume of information (e.g., there are over 400 items in their catalogue) could cause confusion. Clearinghouse staff, however, do try to help clients weed through the information and choose what is most appropriate by providing their expertise. Another respondent noted that clients sometimes have difficulty distinguishing NGOs from government. This can create a barrier if a client thinks the Clearinghouse is a government agency which then may lead to a fear of being put on a database, resulting in a loss of anonymity. However, according to this respondent, once a client starts dealing with the Clearinghouse this perceptual problem is soon resolved.

Given that the primary clients are AIDS Service Organizations and health agencies, it is believed by respondents that the Clearinghouse has had an important impact on the capacity of local agencies to provide information to their clients. This is particularly true, according to one respondent, for the smaller organizations, as well as for those with diverse jobs (e.g., public health). When these individuals decide to focus on AIDS, they need specific support. Through CANNET, respondents feel the Clearinghouse has had very positive effects on communications among HIV resource centres. Not only is CANNET in touch with the Clearinghouse, but the resource centres within CANNET are more frequently in touch with each other. Respondents were also in agreement that the Clearinghouse has had an effect on the resourcing of health educators as they are seen as being the primary focus of the Clearinghouse. By giving health educators (including those in different countries) better access to resources through one-stop shopping, the Clearinghouse can help them to do their jobs better.

It is the perception of respondents that the Clearinghouse is having at least some effect on the level of knowledge in the various target groups. While acknowledging the difficulty in measuring the effect, respondents feel that with the amount of information they are providing, it would be surprising if there was no effect. Respondents also believe that the Clearinghouse has aided in increasing the capacity of Canadians and target groups to respond to the epidemic. This has been achieved primarily by being able to provide the appropriate resources to all Canadians. It was also noted that, through their partners and by members of the Clearinghouse being involved as players at research meetings, the staff at the Clearinghouse know where the pressure points are (i.e., areas where the epidemic has broken out) and are able to identify the gaps in information.

Respondents also believe that the Clearinghouse has had an impact on the effectiveness of HIV/AIDS prevention and education in Canada. The Clearinghouse is seen to have played a role in providing various groups across Canada with the necessary information they need in order to do their jobs. Another respondent commented that the Clearinghouse has enhanced the effectiveness of HIV/AIDS prevention and education in Canada by centralization of information. Respondents do not feel the Clearinghouse has had as much effect on the effectiveness of care, treatment and support for people living with HIV/AIDS in Canada. Although they continue to distribute documents on care, treatment and support, they do not provide reference services on this.

Respondents were all confident in their belief that clients are satisfied with the services provided by the Clearinghouse. This opinion is supported by "fan" letters they have received from clients expressing their satisfaction, anecdotal feedback and the assessment conducted in 1994. A review of some of the letters indicated that clients have been happy with the materials provided and have praised the Clearinghouse for its speedy service, professionalism and friendliness. The results of the study by J. Phillip Nicholson Policy and Management Consultants Inc. (1994) also show high levels of satisfaction with the Clearinghouse's services among those who use them (e.g., 92 per cent of those who have used the service at least agree somewhat that the Clearinghouse delivers materials in the time promised), although the non-response rate on some of the questions was high (e.g., 62 per cent of respondents answered "don't know/can't say" when asked if they agreed or disagreed that the lending period for materials was sufficiently long enough). In the study, the relatively high non-response rate on some of the questions was attributed to lack of knowledge of specific services of the Clearinghouse.

In Ekos' study of stakeholders, the majority of stakeholder organizations (87 per cent) reported that they had needed services like those provided by the Clearinghouse. Of those groups who were aware of and had needed the services of the Clearinghouse, 83 per cent had used the Clearinghouse. Satisfaction with the accessibility of information through the Clearinghouse was high — three quarters of respondents reported being satisfied with this aspect of the Clearinghouse.

Respondents also acknowledged that, although few in number, there had been some complaints. Complaints received are followed-up and an attempt is made to resolve the problem as this is perceived as a being basic client service. Sometimes the problem is beyond the scope of the Clearinghouse. For example, if the problem has to do with the wording in a pamphlet, then it is the supplier of that product that has to change it. The Clearinghouse may also have its hands tied regarding the delivery of resources on time. If the resources have to come from the supplier before being delivered to the client, for example, then the ability of the Clearinghouse to deliver on time depends on when they get the resources.

A number of lessons learned were noted by respondents. For example, it was noted that it is best to have activities centralized as it will increase the ease and accessibility of needed information. Another lesson learned was that you can be a victim of your own success. The high demand for resources at the Clearinghouse has resulted in the need to institute cost recovery measures. The importance of having comprehensive funding over funding on a year-to-year basis was also noted. In terms of success stories, the extent of the demands that the Clearinghouse staff have met (e.g., 1.5M documents sent, 14 conferences attended between April 1996 and March 1997, numerous searches completed) is evidence of the success of the Clearinghouse.

Views on the Clearinghouse from Other Stakeholders

Internal Review Results

According to key informants in the internal review, the Clearinghouse is viewed as an important resource by non-governmental organizations. Many of the respondents in the regions also mentioned utilizing this resource for themselves, as well as passing the information along to various non-governmental organizations. It is an effective central distribution point for information to community-based organizations. Some of the regional Health Canada respondents provided the example of calling the Clearinghouse to determine whether a certain resource has been previously prepared with the intention of avoiding "reinventing the wheel".

The Clearinghouse is perhaps weak in its marketing of services and the definition of its core audience. The Clearinghouse is viewed as not having fully utilized its access to public health units across the country to convey new and emerging information around HIV/AIDS. It was noted that the Clearinghouse has limited utility for school-based projects and should be targeted to people working in the field. Other concerns with the Clearinghouse include the implementation of user fees (thereby becoming less accessible to non-governmental organizations). The efficiency of the delivery of Clearinghouse services and other AIDS programming offered by the CPHA is also questionable.

Provincial Survey and Inventory Results

According to the vast majority of provincial/territorial respondents, the Clearinghouse has been very effective and useful. These respondents described the Clearinghouse as a good central source of information, that provides easy access to a range of resources without having to search. These respondents also agreed that there is a continuing role for the Clearinghouse. According to NGO representatives, the Clearinghouse has helped them to find out what approaches have been used elsewhere with success, and has helped them to avoid "reinventing the wheel". Most respondents also felt that the Clearinghouse has helped them save time. While the information available through the Clearinghouse is generally available elsewhere, it is difficult to find and would require some searching.

A few respondents expressed concern that users now have to pay for access to some materials. These respondents feared that cost recovery will limit access for small organizations with limited funds.

Two respondents disagreed that the Clearinghouse was useful and effective. One respondent indicated that they had not found it useful, while the second felt that the Clearinghouse is redundant given current technology. This respondent argued that the Internet and e-mail make it easy to transmit and share information and thus, that the Clearinghouse is no longer necessary. A few respondents did note that some of the information provided by the Clearinghouse is now available on the Internet, but that one must have the technology and access to obtain it.

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 8:
CATIE — AIDS Treatment Information Network

September 2, 1997

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 8: Community AIDS Treatment Information Exchange (CATIE)

Background and Context

The Community AIDS Treatment Information Exchange (CATIE) is a non-profit community-based organization that aims to help people living with HIV/AIDS and their caregivers, including physicians and other health care professionals, make informed decisions regarding their health care by providing them with the information they need on treatments. CATIE's commitment to this objective is clearly articulated in their mission statement:

> *CATIE is committed to improving the health and quality of life of all people living with HIV/AIDS. By providing HIV/AIDS treatment information, CATIE encourages people living with HIV/AIDS to be actively involved in making decisions and developing strategies to optimize their health care.*
>
> *We are committed to providing services defined by the ongoing participation, advice and expressed needs of all communities of people living with HIV/AIDS.*

Information on treatments, in both official languages, can be accessed through a 1-800 service, CATIE's web site and through CATIE's publications (which can, in turn, be accessed either through the 1-800 service or directly via the web site). Additionally, CATIE plays an advocacy role in the pursuit of improved research and better and easier access to treatments.

CATIE is involved in a number of activities, such as presentations, peer treatment counselling and advocacy. The need for CATIE's activities and the services it provides have been documented in a number of reports. In 1991, a needs assessment involving consultations with people living with HIV/AIDS (PLWHIV/AIDS)[1], was conducted on behalf of CATIE. According to this assessment, the majority of participants indicated that information is the key to dealing with HIV. The authors of this report went further to recommend that CATIE play a lead role in the provision of treatment information.

Three years later, the need for access to treatment information was again identified. In a study on the service and support needs of individuals infected and affected by HIV/AIDS conducted for the Ontario Ministry of Health[2], the need for access to information about symptoms, treatments and medications was identified by 71 per cent of respondents as being extremely important. Of this 71 per cent, 47 per cent felt this need was very or extremely well met and 33 per cent felt it was fairly well met, with 20 per cent indicating it was not well met. Findings from this study also show that women were more likely to feel that this need is not being well met than were men (i.e., 29 per cent of women indicated feeling this need was not well met compared to 19 per cent of men).

In addition to the need for access to treatment information, other needs of PLWHIV/AIDS have been identified which CATIE can play a role in addressing. For example, a study by the Ontario Ministry of Health[3] noted the need to increase

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1. Foley, R., *AIDS Treatment Information Needs Assessment*. Toronto, 1991.

2. ARA Consulting Group, *The Service and Support Needs of Individuals Infected and Affected by HIV/AIDS*. Toronto, 1994.

3. Ministry of Health, *Building on Our Strengths: Focusing our Efforts — Ontario's HIV/AIDS Plan to the Year 2000*. Toronto, 1993.

better access to clinical trials for people with AIDS living in smaller and more isolated areas. This is particularly important as most drugs used are still in the experimental stage. This report also stated the intent of the provincial government to encourage treatment information exchanges, such as CATIE, as a means of ensuring access to the best possible medical care and treatments for PLWHIV/AIDS.

AIDS Treatment Information Network

CATIE's AIDS Treatment Information Network, more commonly known as the Network, is the primary focus of this case study. According to the Network's vision statement (*1996/97 Budget Proposal*):

> *The HIV/AIDS Treatment Information Network will provide reliable, comprehensive, timely, useful and easily accessible information on the diagnosis and treatment of HIV infection and related conditions, and on clinical advances in the field of HIV infection, primarily to persons with HIV or AIDS and their professional and non-professional caregivers.*
>
> *The HIV/AIDS Treatment Information Network will contribute to the optimal clinical management of HIV infection in Canada by providing relevant information thus assisting persons with HIV and their caregivers in making informed decisions about the allopathic and non-allopathic therapeutic options available.*

To meet the objectives of the vision statement, 12 guiding principles have been put forth:

1) The information will be easily accessible by persons with HIV, their caregivers and other concerned individuals.

2) The service will be responsive to the changing informational needs of both persons with HIV and their caregivers.

3) The service will strive to develop successful working partnerships with the communities of users and professional health organizations.

4) The service will be client oriented and client driven.

5) The information provided will include both drug and non-drug therapies.

6) The information provided will include both medical and complementary therapies.

7) Information will be provided on where to access care.

8) The information will be reviewed by recognized authorities for both medical and complementary and traditional therapies.

9) The information provided will be available through multiple methods of access, including measures to provide confidential, anonymous access to the extent possible.

10) The information will be accessible to persons across Canada, in both urban and rural areas.

11) The service will be responsive to "breaking news" (both new research findings and new stories) and will disseminate new information quickly and efficiently.

12) All information generated by the service will be made available in at least French and English.

The history of the Network can be traced back to before the first phase of the National AIDS Strategy, when the need for a treatment registry was first identified by the AIDS activist community. In the fall of 1988, AIDS Action Now! (CATIE's parent organization) led the lobby with the support of a coalition of AIDS organizations under the Canadian AIDS Society (CAS). In 1990, it was announced that such a registry would be included in Phase One of the National AIDS Strategy. Between 1990 and 1994, two attempts to establish the registry were made and failed. During this time, the name of the service also changed from the Treatment Information System for AIDS/HIV Infection (TISAH) to the AIDS Treatment Information Service (ATIS). In November 1993, following the decision to disband the registry for a second time and in light of the recognized continued need for such a service, CATIE, along with other community groups, was invited by Health Canada to submit a proposal. In January 1994, an interim contribution agreement was signed by CATIE and Health Canada (*Contribution Agreement Between CATIE and Health Canada*).

During the implementation process, documents from the first two programs were reviewed by a working group established by CATIE's Board of Directors. The primary recommendation to come from this review was that CATIE needed to conduct a national consultation across all regions with potential users to determine how needs varied according to, for example, region, gender and culture[4]. Participants at these consultations included medical, scientific and research organizations, AIDS service representatives, physicians, alternative treatment practitioners and individuals diagnosed with HIV. These consultations addressed issues around the content and format of the information to be provided, access issues, communication issues and evaluation issues. Examples of some of the recommendations include:

- ☐ *Content: topics*
  - treatment information of all kinds
  - Basic HIV/AIDS information primarily for the newly diagnosed
  - referrals and resources on all levels

- ☐ *Content: format*
  - be sensitive to cultural and regional terminology
  - maintain neutrality of information
  - present different levels of information

- ☐ *Access: ways and means*
  - basic modes to be established simultaneously (i.e., telephone 1-800 line, with collect call and TTD/TTY options; fax 1-800 line; mail, with courier options)
  - computer modem access via a 1-800 line connecting with a treatment information specialist and the ATIS database
  - distribution of print (e.g., newsletter with graphics and pictures)

- ☐ *Access: principles*
  - no cost to the user
  - live personal contact
  - confidentiality and comfort levels are respected

- ☐ *Evaluation*
  - solicit ongoing feedback from consumers
  - evaluation results should assist in driving the service
  - use both internal and external reviews

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[4] Community AIDS Treatment Information Exchange (CATIE), *ATIS Consultations: National Report*.

- ☐ *Communications: promotion*
  - depict all potential user groups in advertising
  - develop a pamphlet advertising ATIS
  - explore all options and outlets

- ☐ *Communications: outreach*
  - give priority to people not currently accessing AIDS service organizations
  - give priority to those in rural and isolated areas
  - make it clear that this is a community-based initiative

There were also other, more general, recommendations, such as develop realistic, clear limits to the efficiency of the service and take "baby steps" to ensure that what is put in place is done well. In implementing the service, the many recommendations to come out of these regional consultations were followed.

A National Advisory Committee has been established to provide CATIE's Board of Director's with guidance regarding the functioning of the Network. This committee is comprised of:

- ☐ one member from either the Acupuncture Foundation of Canada, the Canadian Naturopathic Association and the Chinese Medicine and Acupuncture Association of Canada (the seat rotates between these three groups);

- ☐ a total of 12 representatives from HIV communities located in British Columbia and the Yukon Territory, Alberta and the Western Territory, the Prairies (Saskatchewan and Manitoba), Ontario, Quebec and the Eastern Territory, and Atlantic Canada — one representative from each region must be HIV+ (representatives are selected from nominations made by AIDS service organizations and AIDS community groups);

- ☐ representatives from National Partners: Canadian Haemophilia Society, Canadian Nurses Association, Canadian AIDS Society, Canadian Public Health Association, Canadian Association of Social Workers, Canadian Association for HIV Research, College of Family Physicians of Canada and Canadian Medical Association.

- ☐ one seat is selected by CATIE's Board of Directors from nominations provided by an under-represented group; and

- ☐ one member from CATIE's Board of Directors.

Health Canada is also represented in an ex-officio capacity. (*The HIV/AIDS Treatment Information Network National Advisory Council Terms of Reference*).

The National Advisory Committee meets twice a year, although guidance may be solicited at other times via telephone or mail (*HIV/AIDS Treatment Information Network 1996/97 Budget Proposal*). In undertaking its responsibilities, the Committee is guided by the Network's vision statement and guiding principles.

For the fiscal years 1993/94, 1994/95 and part of 1995/96, funding was provided to CATIE by Health Canada for consultations and implementation of the Network. In 1993/94, they received $150,000, in 1994/95, they received $514,381, and in 1995/96, they received $1,575,000 (*CATIE Financial Statements*). As noted, only part of the 1995/96 funds were for implementation; as the Network was operational as of July 1, 1995, thus the funding would then have become operational funding. In 1996/97, the first full year the Network was fully operational, CATIE received $1,600,000 in operational funds from Health Canada.

Given the uncertainty surrounding secured government funding, CATIE has taken a proactive role in finding new funding sources which will allow it to both maintain the high quality services of the Network and to expand its services (*CATIE in 1997/98 — Building on a Solid Base*). Funding from private sources, however, is not expected to replace public funding, but to complement it (*Policy Statement on Corporate Fund Raising*). As a first step, CATIE contracted with Ketchum Consulting to undertake a fund raising planning study. This study determined the fund raising potential of CATIE (e.g., personal image of CATIE is perceived to be good to very good) and identified challenges that need to be addressed (e.g., lack of public awareness of its range of programs and services to the HIV/AIDS community, limited philanthropic appeal)[5]. Ketchum Consulting also developed print materials to be used in CATIE's fund raising campaign (i.e., *Case for Support, Planned Giving Brochure*). While the need to find new funding sources is recognized, there are concerns (e.g., there may be a perception of bias in CATIE's information products and services if they are extensively funded by, for example, pharmaceutical corporations) (*Policy Statement on Corporate Fund Raising*). Consequently, in consultation with the National Advisory Committee, strict funding source acceptance guidelines have been established.

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[5] Ketchum Fund Raising Counsel, *A Fund Raising Planning Study*, October 1996.

Needs and Implementation

The primary need being addressed by the Network, as identified through the needs assessments, is the need for knowledge of the best treatment options so that PLWHIV/AIDS can make informed decisions about their treatment. Respondents noted that while programs and services dealing with prevention and education are crucial, the key factor for those who already have the disease is the ability to manage their own care. It was further noted that this need for knowledge is enhanced by the fact that treatment information for HIV is extensive, complex and is being developed at a very fast pace. Added to this is the fact that HIV is more complicated than other health issues as it is a relatively new illness that is bound up in complicated social conditions.

CATIE provides three integrated services through the Network: 1-800 telephone consultation service; print publications[6]; and Internet service. The 1-800 number telephone consultation service is accessible to callers 60 hours a week. The Treatment Information Consultants (TICs) and volunteers who respond to the 1-800 number calls have the ability to provide immediate answers to a wide range of information requests or, if necessary, will refer callers to other resources (*CATIE in 1997/98 — Building on a Solid Base*). They will also research treatment issues for callers, provide follow-up with a return phone call or send out any print materials requested. It is important to note that all TICs receive an intensive training course before being allowed to respond to calls. Areas covered in this training include (*Treatment Information Consultant Training Program*):

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[6] A listing of CATIE's publications are provided at the end of the case study.

- ☐ HIV/AIDS treatment information;
- ☐ counselling/advocacy skills;
- ☐ research skills;
- ☐ writing and editorial skills; and
- ☐ information technology skills.

Every time a call is received, information is collected as to the type of call (i.e., telephone, fax, e-mail), the date, start and end time, sex, language[7], caller group, reason for the call (including type of treatment information requested and any notes), action taken (including any notes), how they heard about the Network, location of the call and whether this is a first time call or a repeat call. There is also space for anecdotal information where people can relay some of their own experiences with different treatments. As it is the intention of CATIE to have the Network become a true *exchange* of information, this last category is of particular importance in reaching this goal. The collection of this information allows CATIE to track calls for statistical purposes and to determine shifts in trends regarding, for example, information requested and caller groups.

People can also access treatment information through CATIE's web site. In establishing the site for the Network, a key first decision was to offer character-based access to documents as a platform to build other services. This allowed people to have free access to the site through public libraries. Additionally, documents can be downloaded and, in fact, CATIE encourages people to do this and pass them on to others. To make the information on the web site as accessible as possible, documents are presented in rich text format so that they can be read by either IBM or MacIntosh and in either WordPerfect or Word. Documents are also presented in a graphic mode for people who have up-to-date computer technology. It was noted, however, that CATIE's policy is not to emphasize the web site, but to emphasize the telephone service instead. The reason for this is that, although the number of Canadians using computers is increasing exponentially, the number of computers in households is still not high.

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[7] While English and French are the main languages in which services are provided, some TICs are fluent in other languages, such as Spanish and Italian.

While the 1-800 number service is the most visible component, the Network is perceived by study respondents to be a continuum of services. The data base, for example, was created to assist with responses to the 1-800 calls and the web site was created so that the data base, as well as all other CATIE publications, would be available through the Internet. Having these three services so interlocked has, according to respondents, created an interesting dynamic in that all of them had to progress simultaneously. In addition to these original three services are the in-person presentations, workshops and skills building seminars in which CATIE is becoming more increasingly involved. CATIE also provides Peer Treatment Counselling to those wishing to discuss treatment concerns with someone who are themselves HIV positive. It is the perception of all interview respondents that the services being provided through the Network are addressing the most important areas of need as identified above.

The Network's clientele consists primarily of people with HIV/AIDS (PHA), AIDS service organizations (ASO), family and friends of PHAs and health care providers, including clinics and institutions. Exhibit 1 below presents a breakdown of the calls received in 1996/97 by caller group, language and sex. As the table indicates, the majority of calls come from people living with HIV/AIDS, males and Anglophones. While 92 per cent of these calls were made via the 1-800 number, some were received via e-mail, fax and drop-in (see Exhibit 2). These alternative ways of accessing the Network's services are particularly notable in the last three months.

EXHIBIT 1
CATIE Network Calls from April 1, 1996 to March 31, 1997

Date	Total Calls	Caller Groups					Gender		Language	
		PHA	Partners, Family, Friends of PHA	ASO	Health Care Provider	Other	Male	Female	English	French
1996										
Apr	189	79	15	23	0.00	56	123	66	148	40
May	224	90	21	29	29	49	130	94	188	36
Jun	196	91	19	23	25	40	117	79	174	22
Jul	306	119	30	46	28	64	191	104	243	52
Aug	233	124	23	26	22	28	151	75	175	51
Sep	233	148	28	18	14	30	165	68	174	59
Oct	335	168	32	41	28	71	209	126	260	75
Nov	330	163	27	40	28	76	208	122	247	83
Dec	272	140	44	22	23	47	188	84	202	70
1997										
Jan	388	169	57	51	47	68	229	159	302	86
Feb	390	188	44	54	36	80	257	133	309	81
Mar	374	170	35	52	45	94	232	139	291	79
Total	3,470	1,649	375	425	339	703	2,200	1,249	2,713	734
% of total calls	100%	48%	11%	12%	10%	20%	63%	36%	78%	21%

Source: Data extracted from CATIE database

Note: "Other" includes media, government, pharmaceuticals and students.

EXHIBIT 2
Distribution of CATIE Network Calls by Type of Contact Between April 1, 1996 and March 31, 1997

Date	Total Calls	Type of Contact			
		Telephone	E-mail	Fax	Drop-in
1996					
Apr	189	185	0	0	4
May	224	216	1	1	6
Jun	196	191	0	0	5
Jul	306	306	0	0	0
Aug	233	233	0	0	0
Sep	233	33	0	0	0
Oct	335	335	0	0	0
Nov	330	330	0	0	0
Dec	272	272	0	0	0
1997					
Jan	388	368	20	0	0
Feb	390	367	14	2	7
Mar	374	345	21	1	7
Total	3,470	3,181	56	4	29
% of total calls	100%	92%	2%	0%	1%

Source: Data extracted from CATIE database

As already noted, the 1-800 number is the most visible component of the Network. However, it is felt by respondents that the web site and the print material are very much interlocked with the 1-800 number. Consequently, all the services provided through the Network, as well as CATIE's products (e.g., fact sheets), are seen as being key to the Network's mandate.

It is the perception of those interviewed that the awareness of CATIE's Network is increasing. While it is felt by all respondents that awareness levels are high among the organized AIDS community and health care organizers, it is felt that the awareness level amongst the general public and caregivers (i.e., friends, family, partners and colleagues) is not as high. Individuals must be connected to a larger service to be aware of the Network's existence. Awareness of the Network among the organized AIDS community and health care organizers, however, has, according to a couple of respondents, aided CATIE's Network in achieving national recognition. As indicated in Exhibit 3, while the majority of the Network calls still originate in Ontario, the number of calls from other regions is on the rise.

All respondents were in agreement that the services provided by the Network were consistent with the mandate, mission, objectives and priorities that were agreed to by stakeholders. According to one respondent, as it is easy to go off on tangents, the mission statement is frequently re-visited. It was also noted by a couple of respondents that, through the National Advisory Committee, they have received confirmation that the original information from the national consultation regarding the need for their services (i.e., 1-800 number, print publications, Internet) is still relevant. It was further noted by one respondent that maintaining consistency with the Network's mandate and mission has been aided by the fact that it has always been very clear as to what CATIE would be doing.

EXHIBIT 3
Distribution of CATIE Network Calls Across Regions Between April 1, 1996 and March 31, 1997

Date	Total Calls	Region of Callers							
		Ontario	Quebec	Atlantic	Prairies	B.C.	NWT/ Yukon	Out of Canada	Not Specified
1996									
Apr	189	114	34	9	8	10	1	4	9
May	224	138	30	12	11	12	1	7	13
Jun	196	130	19	9	15	9	1	5	8
Jul	306	174	51	12	15	11	1	7	34
Aug	233	124	48	14	10	17	2	6	12
Sep	233	125	62	8	13	15	1	6	3
Oct	335	175	80	14	22	24	2	12	4
Nov	330	203	73	8	12	21	2	10	1
Dec	272	153	64	5	16	14	2	9	9
1997									
Jan	388	195	84	11	20	34	2	35	7
Feb	390	193	96	15	26	33	0	19	8
Mar	374	210	79	16	23	16	1	22	7
Total	3,470	1,934	720	133	191	216	16	142	115
% of total calls	100%	56%	21%	4%	6%	6%	0%	4%	3%

Source: Data extracted from CATIE database

Interview respondents identified a number of ways to stay abreast of needs. At the very beginning, as has already been noted, CATIE undertook a national consultation process with individuals at the grassroots level to clarify the need. The results of these consultations indicated that people wanted a service that was much more comprehensive than the registry which had been initially planned and attempted twice before. Since the Network has been implemented, respondents indicated that needs are determined based on the information individuals using the 1-800 service are requesting (i.e., provides an indication as to what the "hot topic" is) and input from the National Advisory Committee. According to some respondents, a lot of trust is put into the National Advisory Committee as members of the Committee were carefully selected to give CATIE the broadest range of input to ensure their service was not being developed in a vacuum.

In addition to these sources of input, needs are identified through evaluations that have been conducted (e.g., telephone survey), focus groups with PLWHIV/AIDS, conferences, anecdotes and the tracking system that has been implemented for the 1-800 service. Also of importance in identifying needs is the involvement of the staff and volunteers on other committees and in the community at large. Respondents commented further that, as staff, volunteers and CATIE's Board members were aware that the type of information they were providing would change, the Network was created to allow for change.

According to respondents, CATIE's priorities and objectives regarding the Network are reviewed on a continual basis. Some of the key times when this occurs is at the National Advisory Committee meetings which occur every six months and during the development of the workplan. They also receive national input through the program's Health Canada representatives. Additionally, it was noted that, when the "landscape" around treatment changes, the media picks up on it and that keeps them "on their toes".

CATIE has undertaken marketing initiatives since the first networking and outreach strategy was developed in the fall of 1995 (*Networking and Outreach*, October, 1995). Since that time, CATIE's promotional activities have included the CATIE newsletter, direct/bulk mail, paid and free advertising, posters, presentations, cross-promotions and Internet promotions (*Summary of Marketing Initiatives - 1996/97*, May 1997). In-house promotional materials include pamphlets, business cards, business card stickers and flyers (*CATIE Promotions*, January 1997). While CATIE's primary marketing strategy has been aimed at PLWHIV/AIDS and their caregivers (both professional and non-professional), attempts have been made to design strategies for those populations that are hard to reach such as aboriginals, rural people, ethnocultural communities, prisoners and women (*Summary of Marketing Initiatives - 1996/97*, May 1997).

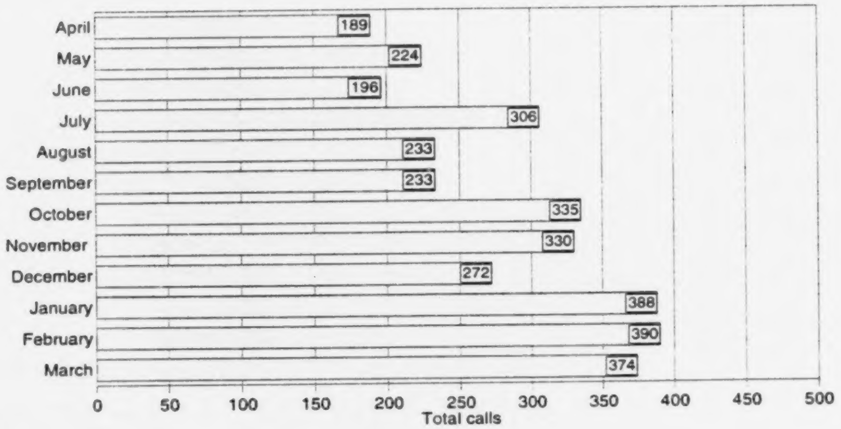
According to respondents, the actual marketing of the Network and its services was undertaken cautiously with the different aspects of the Network being marketed as they were ready. It was indicated by one respondent that, given the failure of the past two registries, CATIE wanted to ensure "they had it right" before undertaking a broad marketing campaign to everyone. Now, the whole package is being marketed. The overall perception of respondents was that this approach to marketing was meeting their needs. One respondent, in fact, indicated that their telephone calls were increasing by five per cent each month.

It is the perception of interview respondents that the need for services provided by CATIE through the Network has evolved significantly. Originally the mode of delivery, as noted by one respondent, was the distribution of print material. This has now changed with the introduction of the web site and people requesting information over the telephone. Respondents also noted a shift in the kinds of calls they receive, with more resources being spent on giving people the tools they need to make decisions rather than just giving information (i.e., helping them deal with the confusion surrounding treatment and how to discuss treatment options with their physician, family and friends). This respondent further noted that the extent of the information available and the number of sources for information has resulted in CATIE taking on the role of "tour guide".

CATIE's clients have also grown and evolved since the Network was introduced. Some respondents noted that there has been an increase in use by health care providers, AIDS service organizations and women. Additionally, respondents noted that there has been a geographic shift with an increase in calls from rural areas. Changes in clients are reflective of epidemiological shifts as well. That is, according to respondents, there is now a higher proportion of substance users, women and youth contracting HIV/AIDS, resulting in more calls made by these individuals to the Network.

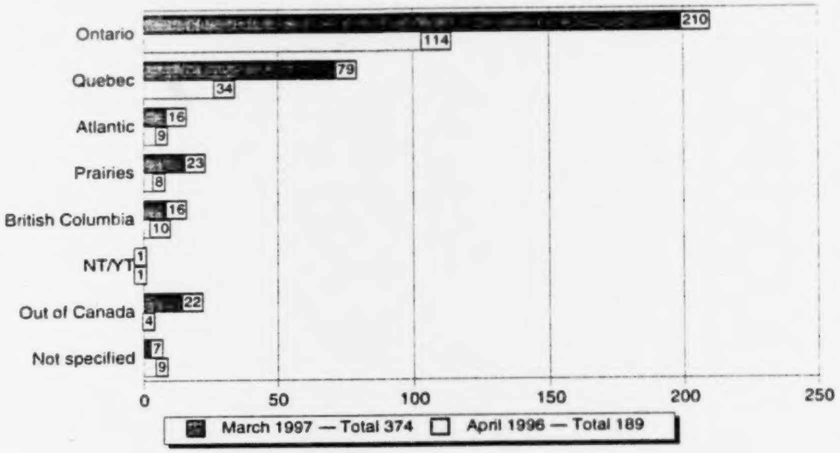
Respondents were all of the opinion that there is a continued need and growing demand for the services provided through the Network. Evidence of this can be seen in the increasing number of calls over the past year, as well as the number of documents delivered by the web site. While this increase can be seen from the numbers presented in Table 1, they are graphically reproduced in Exhibit 4 for clarity. While there is some variation, it is clear that the number of calls is increasing. This increase in demand is also clearly evident when comparing the number of calls received from each region in April 1996 to the number of calls received from each region in March 1997 (see Exhibit 5). In some instances, the number of calls has doubled. As also noted, the use of the web site has also increased significantly over the past year. The number of documents delivered by the web site between May 1996 and March 1997 is presented in Exhibit 6.

EXHIBIT 4
CATIE Network Calls
from April 1, 1996 to March 31, 1997



Source: CATIE databases

EXHIBIT 5
CATIE Network Calls by Region



Source: CATIE databases

The three main target populations for CATIE's Network are PLWHIV/AIDS, health care providers (i.e., physicians and nurses) and caregivers. The number of people currently living with HIV/AIDS as of March 1997 is estimated at 41,000 people (*Canadian HIV/AIDS Stats*) and the number of primary care providers was estimated by respondents to be approximately 30,000 in general, including 800 who identify themselves as providing HIV care. Respondents were not, however, able to provide an estimate of the number of caregivers as there is no reliable way of knowing.

EXHIBIT 6
Documents Delivered by Web Site
Between May 1, 1996 and March 31, 1997

Documents	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
Bilingual "Splash" page	204	235	388	465	399	581	734	657	834	838	3,517
Table of Contents	117	131	703	867	1,072	1,385	1,709	1,754	2,150	2,546	4,763
Table des matières	28	25	77	100	160	202	271	227	279	352	787
What's new / Quoi de neuf	0	72	1,341	1,860	2,246	3,450	5,047	4,336	5,818	7,635	15,499
Fact sheets / Feuillets d'information	0	0	120	183	217	459	1,369	864	1,572	1,921	2,240
Managing Your Health / Vous et votre santé	0	0	0	0	16	136	304	592	1,491	1,855	3,434
HIV+ Peers as Treatment Counsellors	0	6	55	48	59	27	40	47	68	59	129
Guide to HIV/AIDS Clinical Trials / Guide aux essais cliniques VIH/sida	23	18	180	186	159	240	395	223	279	143	248
Treatment Update/Traitement SIDA	4	0	251	408	416	943	1,529	1,392	1,869	1,870	3,122
List of current clinical trials/liste des essais cliniques en voies	5	5	139	143	121	199	350	208	292	123	137
CHAMP Drug directory	0	0	47	181	1,063	1,285	2,272	1,622	2,654	3,527	7,086
HIV/AIDS Treatment Thesaurus/ Thésaurus des traitements VIH/sida	0	4	325	301	370	404	594	656	1,258	1,340	2,348

Documents	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
List of Internet links/Liste des liens Internet	73	100	354	372	478	525	669	544	724	851	1,496
Files downloaded from server	0	0	0	0	0	0	4	135	362	390	625
Total documents read from database *	0	0	0	0	0	0	0	0	451	2,240	14,067
Total other documents read **	105	205	2,812	3,682	5,145	7,668	12,573	10,619	16,387	19,714	36,364

Source: CATIE Website database

* All documents were moved from the NCSA web server to the Notes web server during March. Although increasing accessibility to documents, this change significantly reduced the ability to differentiate one from another in the access log. CATIE is developing an analysis tool for the Notes log which will restore this ability.

** This number does not include lists of documents, hits on graphic images, or documents read by people in CATIE's office.

Generally speaking, it was felt that the Network's activities do not overlap with those of other organizations. According to some respondents, CATIE has been very careful to avoid that problem. In instances where there is a potential for overlap (e.g., Atlantic Information Network), CATIE uses this as an opportunity to build partnerships and to build off what is being done. In fact, it is the perception of those interviewed that CATIE's Network fills a gap in the services being provided by others, especially the smaller ASOs, as they have the ability to marshal larger amounts of resources together, to review more sources of information and to maintain more information. They are also able to offer the information back to a wider audience and through more avenues. Some respondents believe that there is nothing else like CATIE's Network in Canada in terms of the amount of resources on AIDS treatment that can be pulled together. It was also noted that the Network is the only national, fully bilingual information network that provides its range of services.

The Network's infrastructure is perceived by interview respondents to be more than adequate. While the movement from a small to a large organization (i.e., from five people to 20) made the initial stages of development a challenge, respondents felt that a strong foundation had been built at all levels (e.g., financial, informational). In terms of the management of the Network, a policy and procedures manual has been developed and roles and responsibilities have been defined. Careful attention was also paid to the development of the information resources. Two pieces are perceived to be the key to the Network's infrastructure: 1) the careful planning and management of the information management system; and 2) the information technology system.

The Network's link to NAS-II priority-setting, planning and review processes is seen by respondent's to be primarily through the program's Health Canada representatives. In addition to communicating with these representatives a minimum of twice a month, a Health Canada representative also sits on the National Advisory Committee as an observer.

While cost-effectiveness data are not available, it is the perception of all respondents that the Network is very efficient. One respondent noted that acceptable administration costs for NGOs is believed to be between 14 and 20 per cent. The cost of the administration of the Network is currently four percentage points below that. This respondent further noted that there are only two staff members who have nothing to do with direct service delivery. Respondents also commented on the constant review of the Network's overhead. Last year, in fact, the Network was able to reduce its overhead by $190,000. In-kind contributions, donations, rebates and non-government grants have helped CATIE keep costs down. The total value of the in-kind contributions as well as the donations, grants and rebates since 1995/96 are presented in Exhibit 7.

One of the primary assets of CATIE, and one which has allowed it to keep costs down, is its volunteers. CATIE has a very dedicated group of volunteers which allows it to provide the Network's services to the extent they do. There are a total of 50 volunteers, 37 of which are active[8]. Of the total number of volunteers, 35 are new. The number of volunteers per activity as well as the number of hours donated by volunteers is presented in Exhibit 8. It was the perception of two of the respondents that the two previous attempts at implementing a registry could never have provided the services the Network currently does because they did not have volunteers.

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[8] These statistics do not include Board members who do not participate in other capacities than on the Board of Directors or Committees.

EXHIBIT 7
Listing of Revenue and In-Kind Donations of Goods and/or Services

	1995/96	1996/97	1997/98	Total
Donations	$15,361	$3,500	-	$18,861
Fund Raising Revenue	$12,464	$8,198	-	$20,662
Non Government Grants	$3,000	$63,000	$150,000	$216,000
Rebates	$46,628	$28,421	-	$75,049
Equipment				
Pitney Bowes-folding machine	$2,500	-	-	$2,500
Xerox — copier	$3,000	-	-	$3,000
Furniture				
InKind Canada — desk/chairs	$2,000	$3,000	-	$5,000
Printing House — photocopier	-	$2,000	-	$2,000
InKind Canada -shelving	-	$1,000	-	$1,000
InKind Canada — artwork	-	$500	-	$500
Private — kitchen appliances	-	$1,000	-	$1,000
Services				
IJW Construction — rebate	$28,000	-	-	$28,000
Xerox Canada — rebate	-	$10,000	-	$10,000
Pharmaceutical Ad Campaign	-	-	$300,000	$300,000
Discounts				
Office Supplies	$4,336 (20%)	$7,461 (40%)	-	$11,797
The Printing House	$7,570 (15%)	$5,452 (15%)	-	$13,022
Sprint Canada	$2,611 (40%)	$3,638 (40%)	-	$6,249
Total Values Received	$127,470	$137,170	$450,000	$714,640

Source: Data provided by CATIE

EXHIBIT 8
Number of CATIE Volunteers by Activity

Number of Volunteers	Type of Activity	Hours of Service
5	Committee*	155
9	Administration	460
11	Counselling	1,530
10	Research	2,600
1	Translation	25
6	Other	220

Source: Data provided by CATIE

* These statistics do not include Board members who do not volunteer in other capacities than on the Board of Directors or Committees.

Respondents also indicated that potential alternatives for delivering the services of the Network are always taken into consideration, both at the individual level, as well as in terms of the four services as a whole (i.e., 1-800 number, Internet, print material, presentations). For example, CATIE has switched telephone companies for its 1-800 number as the savings were 40 per cent or more. In fact, the cost savings on one of their recent telephone bills was 54 per cent. They also send single copies of their print publications to AIDS organizations and ask them to copy them for their clients. In fact, all CATIE information products have a permission to reproduce notice on them. One of the growing strengths of the Network is perceived by respondents to be delivery of services via the Internet, which saves in administration, processing, copying and mailing costs. AIDS organizations are also encouraged to download documents and photocopy them for their clients.

Impacts on Access

There is consensus among respondents that the Network has been very effective in improving access to information about HIV/AIDS treatment. In terms of the 1-800 number, it was noted by respondents that the number of telephone lines has been expanded as have the hours. The web site is another way in which access to information has been improved, particularly given that documents can be either read or downloaded. It is also the perception of respondents that the information provided by the Network is both reliable and timely. The reliability and timeliness of the information is, in fact, seen by some respondents as being the hallmark of their success. According to these respondents, their resource library is not only larger than anyone else's treatment resource centre, it is also up-to-date. In addition to the library, there is a "What's New" section on the web site which is updated frequently. Through the Internet, individuals can also subscribe to the "What's New" feature and also to a journal scan which contains all the journal articles which CATIE has become aware of that week. In terms of reliability, fact sheets written by CATIE staff are reviewed internally for accuracy, as well as by at least one outside expert.

While respondents were of the opinion that the Network's telephone service was unique, they were aware of other places that offer services similar to it. For example, some AIDS organizations provide information on treatment. It is the perception of respondents, however, that the services provided by these other organizations is not nearly as comprehensive as that provided by the Network. It was noted, for example, that the majority of AIDS service organizations deal with numerous topics, whereas the Network deals with just one: treatment. Consequently, the Network's information on treatment is much more extensive and comprehensive than that provided by other AIDS organizations. It was also noted that there are a variety of web sites dealing with HIV/AIDS. As there is little help in navigating web sites, CATIE tries to help people to understand which sites are good for what.

Partnerships and collaborations are seen as being key to the development of the Network (*Report on Collaborations & Partnerships*, May 1997). As such, numerous partnerships and collaborations have been undertaken and, according to respondents, have been both effective and cost-effective. Partners include:

- ❑ National Partners
  - Canadian Aids Society
  - Canadian Treatment Advocates Council
  - Canadian HIV Trials Network
  - Canadian HIV/AIDS Mentorship Program
  - Canadian Public Health Association — National AIDS Clearinghouse
  - Canadian HIV Resource Centre Network
  - Canadian Haemophilia Society
  - Health Canada

- ❑ National Linkages
  - National Advisory Committee

Partnerships formed with these groups have resulted in collaborations on specific projects such as the development and delivery of programs, exchange of information on topics such as clinical trials education, participation on committees and publication of national databases on the Network's web site (e.g., the National Library of Medicine database on HIV medicines). In addition to these national level partnerships, respondents indicated that all other service providers are considered as partners. Examples of some of CATIE's most recent partnerships at the local level include:

- ❑ assisted in providing support and training programs for the Atlantic Regional Treatment Information Project. Through this project, staff and volunteers at AIDS agencies across Atlantic Canada will be connected to each other, as well as to CATIE resources through Internet technology.;

- ❑ provided support, information and workshops for the Hamilton AIDS Network Treatment Information Centre;

- ❑ co-sponsored and participated in the 7th Annual "Practical Approaches to Health Care" conference with the Toronto Hospital; and

- ❑ maintained contact with other treatment information services such as British Columbia Persons with AIDS Treatment Information Project, the Comité des personnes atteintes du VIH, the Toronto People with AIDS

Foundation and Consultation Sida to ensure that information is exchanged regularly and that appropriate client referrals are made between the agencies.

The latest technology being used to deliver services is the web site. As has already been noted, efforts have been taken to ensure that information from the web site is accessible to everyone (i.e., information is available in both text-only format as well as high graphic mode). As has also been noted, since its inception, the web site is visited often (e.g., 50,000 documents read during the month of March, 1997) and use of the web site to download documents has increased significantly (see Exhibit 6).

There are 12 guiding principles which give direction to the services provided by the Network, all of which have been, according to respondents, implemented effectively. These principles and their implementation are as follow:

1) **The information will be easily accessible by persons with HIV, their caregivers and other concerned individuals.**

   It is the opinion of those interviewed that the information is very accessible for those who are aware of the Network's existence through the 1-800 number and the web site. Efforts are being made to increase awareness.

2) **The service will be responsive to the changing informational needs of both persons with HIV and their caregivers.**

   Respondents feel that they are very responsive to the changing informational needs. As already noted, as staff were aware that information needs would change, the Network was created to allow for changes.

3) **The service will strive to develop successful working relationships with the communities of users and professional health organizations.**

   According to respondents, and as noted above, partnerships have been undertaken. CATIE's current priority is improving their partnerships and services for health care professionals.

4) **The service will be client oriented and client driven.**

   It is the opinion of respondents that the service is very much client-oriented and client-driven in terms of the design of the services (e.g., initially based on the national consultations), the range of needs being addressed, the language and its accessibility.

5) **The information provided will include both drug and non-drug therapies.**

and

6) **The information provided will include both medical and complementary therapies.**

According to respondents, the kinds of print materials pulled together cover a whole range of therapies, both drug and non-drug. While there is still not a lot on complementary therapies, respondents indicated that they are focusing on this more. One problem with complementary therapies noted by one respondent is that it is difficult to get solid information on them.

7) **Information will be provided on where to access care.**

Respondents noted that this information is available from their 1-800 service.

8) **The information will be reviewed by recognized authorities for both medical and complementary and traditional therapies.**

According to respondents, there are three primary documents produced by CATIE: *Treatment Update*, *Managing Your Health* and the fact sheets. *Treatment Update* was not reviewed as it was written by a recognized authority, *Managing Your Health* has gone through a range of reviews by experts and the fact sheets, as already noted, are reviewed both internally and by at least one external expert.

9) **The information will be available through multiple methods of access, including measures to provide confidential, anonymous access to the extent possible.**

Information is available primarily through their 1-800 service and through their web site. Additionally, CATIE widely distributes a range of print materials. In term of the 1-800 and the web site, confidentially is guaranteed as is anonymity unless information is to be mailed. For those individuals who wish to contact the Network via e-mail, it was noted by one respondent that they are warned that it will not be confidential as their e-mail address will be attached.

10) **The information will be accessible to persons across Canada, in both urban and rural areas.**

As information can be obtained both through their 1-800 number and through their web site, it is the perception of respondents that the information is accessible to everyone across Canada. One respondent did note, however, that it is more difficult to get word of their existence out to rural areas.

11) **The service will be responsive to "breaking news" (both new research findings and new stories) and will disseminate new information quickly and efficiently.**

According to respondents, efforts are taken to make sure that all telephone consultants are on-top of treatment issues. Additionally, there is a "What's New" section on their web site which is up-dated frequently.

12) **All information generated by the service will be made available in at least French and English.**

Respondents indicated that all information generated is translated. Information that is just being reproduced, however, is not always translated. Of note is that CATIE has on at least one occasion been commended on their French translation.

Impacts on Clients

There was consensus amongst respondents that the Network has had a positive impact on the people who have used its services. It is felt that the information provided is being used to educate others, particularly when accessed by AIDS service organizations and doctors and other health care professionals. It is also the perception of respondents that information provided has influenced treatment decisions and case management. Staff have heard anecdotally that the information provided had empowered PLWHIV/AIDS to inform their doctors of treatments. Additionally, doctors have indicated, anecdotally, that information from the Network has influenced treatment decisions (e.g., one doctor has commented that all his patients are carrying CATIE material with them). The Telephone User Survey conducted by CATIE also shows that four out of five respondents felt that the information provided helped them in making a treatment decision.

It is felt by respondents that CATIE has influenced treatment policy and protocols through their participation on advisory councils. In terms of the actual Network information, it was noted that recently information from the Network had been used for a viral load policy. Finally, respondents indicated that links have been created with the Network's resources through its web site (i.e., they review what is available on the Internet and provide direct links to other sites), as well as through referrals made over the telephone. The only problem noted by respondents is that the literacy levels of the information are too high for some individuals. This is not perceived, however, to have created a true barrier as individuals can always contact the Network again.

Respondents were of the opinion that the Network has increased the level of knowledge in the various target groups. This is particularly true of PLWHIV/AIDS. While the impact it has had on the knowledge levels of health care professionals it is not known for sure, the feeling of respondents is that it is increasing. Respondents also believe that the Network has increased the capacity of target groups and individuals to seek out and evaluate treatment information. This is seen as having been achieved in three ways: the information and help provided over the telephone; the skills building workshops; and CATIE's unbiased fact sheets.

Respondents feel that the Network has had a profound effect on the care and treatment for people living with HIV/AIDS in Canada by giving the people who have used their service the treatment information they need. This is also believed to have been achieved through the policy and advocacy role played by CATIE's staff. Additionally, respondents are of the opinion that the Network's activities have contributed to better health outcomes for PLWHIV/AIDS by providing them with the information they need to choose the right treatment.

It is the perception of all respondents that people who contact the Network are generally satisfied with the services that have been provided. This opinion is, in fact, supported by a number of studies undertaken by CATIE to evaluate the Network's services and determine client satisfaction with services provided. The results of these studies, as they pertain to client satisfaction, are as follow:

- ❑ ***A Survey of Subscribers to Treatment Update***: The majority of respondents felt the publication was written in langauge that was accessible, as well as being sensitive to gender, ethnicity/race and age. Respondents also indicated that the layout and structure of the publication enabled them to access the information they needed.

- ❑ ***CATIE User Telephone Survey*** (Anglophone Users):

  - Telephone Consultation Service: 96 per cent of users indicated that the telephone consultation services were easy to reach and 94 per cent felt the telephone consultant understood their needs and provided good support. Ninety per cent of users indicated that the information they received met most of their needs, with 87 per cent reporting that the information was very easy to understand. Of the 52 per cent who were referred to another service, 96 per cent indicated that all or most of their needs had been met by the service to which they were referred.

  - CATIE's Internet Web Site: Of the 20 per cent of users who indicated that they had used the web site, 85 per cent found it very easy to use and 86 per cent felt it met most of their information needs.

  - Information Packages: 80 per cent of the users who have received CATIE's information packages received their packages within one week or less. Eighty per cent felt the information met their needs and ninety-one per cent found the information easy to understand.

  - Usefulness of CATIE's Information for Making Decisions: Eighty-four per cent of the Network's users indicated that they found the information provided to be very useful in making decisions about their own health care or advising a friend or patient.

- ❑ ***Web Site Focus Group Testing***: All three participants were very positive about the web site in general, finding it to be accessible and easy to navigate through.

- ❑ ***Evaluation Print Survey***: Of the 10 surveys that have been returned, four respondents said the information received was very useful with two indicating it was fairly useful. Of the seven who responded about print materials, six said they met most needs and one said they met some needs.

In addition to these surveys, CATIE has received positive feedback anecdotally and through their e-mail. Also, in a review of web sites around the world undertaken by Terry Pook of the HIV Care Programme at St. Joseph's Heath Centre in London, Ontario, CATIE's web site placed amongst the top ten web sites. It was noted by Mr. Pook that CATIE was the best Canadian web site and was a good one to recommend to patients as the material is up-to-date, easy to read and understand, bilingual and Canadian oriented.

According to respondents, the Network has received very few complaints. Steps are taken to avoid complaints. For example, if a Treatment Information Consultant feels that what is being requested by a caller is over their head or if a caller appears unhappy, the calls are referred to the Treatment Information Coordinator. For complaints that have been received, every effort is made to try and find out as much as possible about the problem and to rectify it. Client follow-up may not be possible as it is a 1-800 number and there is no name or telephone number given. If the person has identified themselves, then a letter is written to the individual. Complaints are also brought up at staff meetings to see what can be learned from the incident. One respondent noted that, if the situation was considered to be serious, disciplinary action could be taken. In some instances, there may not be an answer, in which case they would follow-up to see if changes in procedures needed to be made.

As the surveys noted above indicate, the Network has implemented an evaluation plan. The results of the evaluations conducted to date are available and are taken into consideration when reviewing the Network's activities.

A number of lessons learned were noted by respondents. For example, undertaking national consultations to determine what the actual needs of those who would be using the Network and then taking the time to plan it were seen as being very beneficial to the Network's success. The need to maintain this dialogue with users as well as with other national partners was also noted. Paying higher wages to ensure the hiring of the right people was another example of a lesson learned provided by respondents. The only challenge noted by respondents was that posed by information technology and the need to stay on-top of it.

Success stories cited by respondents include:

- ☐ the web site — it is well designed and one of the best HIV treatment resources on the web;
- ☐ the bilingual aspect of the web site is seen as successful based on the feedback received by francophones indicating their satisfaction;
- ☐ as a community-based organization, they have succeeded in getting a very complicated and large project up and running;
- ☐ their ability to change at a moments notice, ensuring that they are up-to-date on their information, has given them credibility; and
- ☐ they have grown from a very typical AIDS organization of five staff to a large organization of 20 staff, 50 volunteers and 15 Board members.

Views of CATIE-Network from Other Stakeholders

Internal Review Results

CATIE's Network is perceived to be a useful source of treatment information, particularly in light of the rapid changes in drug therapies and other treatment regimens. Several respondents noted that the Network supports the notion of consumerism in health. The use of the Network may be somewhat uneven, however, and there may be some duplication with regional organizations. The Network is not operating at full capacity and requires better marketing of its services. Because it is a community-driven effort it has a high level of credibility among the HIV/AIDS community. It should be recognized, however, that the Network is a relatively new organization and it is difficult, at this time to assess effectiveness.

Provincial Survey and Inventory Results

Not all respondents were familiar enough with the AIDS Treatment Information Network (the Network) to respond. Those who did respond agreed that the Network has been effective, and provided many of the same comments as for the Clearinghouse. Respondents noted that it provides easy access to information, and saves them time and money by offering one central access point. Respondents noted that the Network provides up-to-date information useful for a range of groups, including patients and the general public. One respondent also noted that it provides early access to research results, while another noted it provides access to information which is free of bias. While the information available from the Network is generally available elsewhere, it is harder to find and sometimes can only be obtained for a cost. These respondents agreed that there is a continuing future role for the Network.

Stakeholder Survey Results

Overall, 73 per cent of stakeholder organizations reported that they had a need for information about HIV or AIDS treatments. This was higher among community organizations (80 per cent) compared to professional associations (54 per cent). Almost half of respondents (48 per cent) indicated that they had received information on HIV/AIDS treatments from CATIE or the Network.

Sixty-two per cent of stakeholder groups were aware of CATIE's Network and just under half (47 per cent) responded that they had needed services like those provided by CATIE's Network. Once again, awareness and expressed need for treatment information was higher among community organizations compared to professional associations.

Of those organizations surveyed, about one-half had used CATIE's Network to obtain treatment information. Among all respondents, thirty-eight per cent were satisfied with the accessibility of information through the Network. Over half (54 per cent) responded "don't know".

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 9:
Stakeholder Surveys

September 2, 1997

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TABLE OF CONTENTS

1.0 Methodology 1

2.0 Overall Strategy 2

3.0 Coordination 7

4.0 Strategy Components 8

5.0 Group Specific Issues 11

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 9: Stakeholder Survey

In this chapter, results of surveys in the six stakeholder groups are combined for questions regarding the overall Strategy. Issues specific to each stakeholder group are also presented.

1.0 Methodology

Telephone surveys were conducted with samples from each of six stakeholder groups in NAS-II. A total of 201 structured interviews were conducted. Relevant sampling frames were obtained through Health Canada and the CPHA National AIDS Clearinghouse. Sampling was done randomly or until the sampling frame was exhausted. In most cases, the samples consisted of organizations or groups which had had some type of contact with NAS-II, either as a recipient of program funds, as a partner in the development of specific programs, or by having requested information about the Strategy. Upon refusal to participate or after six call-backs, selected organizations were replaced by another of the same type, selected randomly from the same sampling frame. Each interview was conducted with the most senior person available in the organization who was knowledgeable about its HIV/AIDS programming.

Groups surveyed were:

- ❑ Local and Regional HIV/AIDS NGOs and Community-Based Groups (60 interviews);
- ❑ National and Provincial Professional Associations (25 interviews);
- ❑ Canadian HIV/AIDS Researchers (60 interviews);
- ❑ Ethnocultural Organizations (26 interviews);
- ❑ Aboriginal Organizations (30 interviews); and
- ❑ Private Sector Organizations (e.g., pharmaceutical companies).

Telephone interviews were conducted by trained bilingual interviewers through Ekos' Survey Center in Ottawa. Analyses of these data were quantitative.

2.0 Overall Strategy

(a) Continued Relevance

Overall, just over one-quarter of all respondents believe that the current balance in the Strategy is appropriate (i.e., 27 per cent indicating a four or a five on a five-point scale). Just over one-half believe that it is not appropriate (i.e., 54 per cent). The remaining 19 per cent of respondents were unable to comment on the appropriateness of the current balance. Respondents similarly feel that the balance between research in prevention versus research in treatment is also inappropriate; only 18 per cent thought it appropriate, whereas 59 per cent indicated that this balance was inappropriate and 23 per cent did not know.

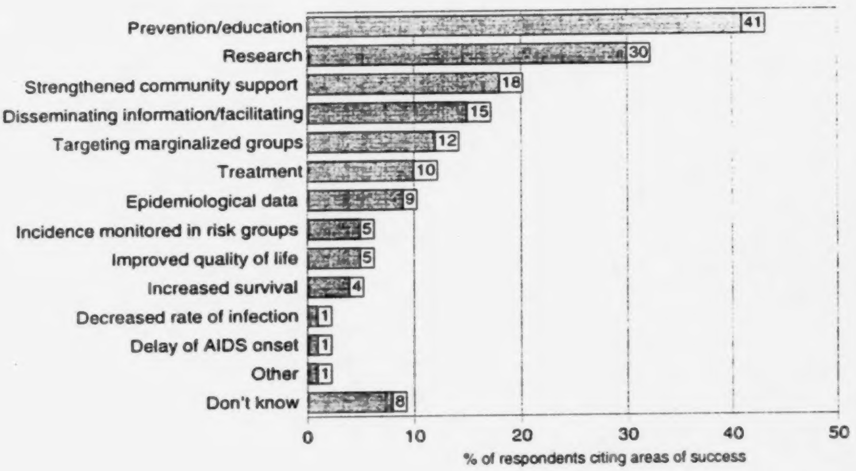
(b) Successes

Respondents were divided on the issue of how well the Strategy has met overall needs of organizations (e.g., in terms of tools, information, materials, and financial support). One-half feel that the Strategy has met their needs quite well (i.e., 49 per cent indicating a four or a five on a five-point scale) and the other half feel that it hasn't met them well.

The key areas of success for the Strategy have been in addressing prevention and education, research, and strengthened community capacity. Respondents were asked to identify the areas they felt the federal Strategy had been especially successful in addressing. These findings are presented in Exhibit 5.1; prevention and education was mentioned most frequently (41 per cent of respondents), followed by research (30 per cent). Strengthened community capacity was also mentioned relatively frequently (i.e, 18 per cent). Although non-response to this question comprised eight per cent overall, it comprised 17 per cent of Aboriginal organizations (or four of 24 organizations).

Unlike the Strategy's successes, few clear themes emerged regarding areas in which the Strategy has not been successful in addressing. Although distribution of information, research (including lack of funding for research) and uncertainty/lack of continuity of funding were mentioned most frequently, responses were fairly evenly distributed among the response categories, with most of the comments falling into an "other category" (Exhibit 5.2). "Other" responses included the following (in no particular order): lack of follow-up upon completion of Strategy phases; lack of behavioral/societal change; lack of education/training for people working in the field; need more emphasis on prevention; public education; First Nations communities.

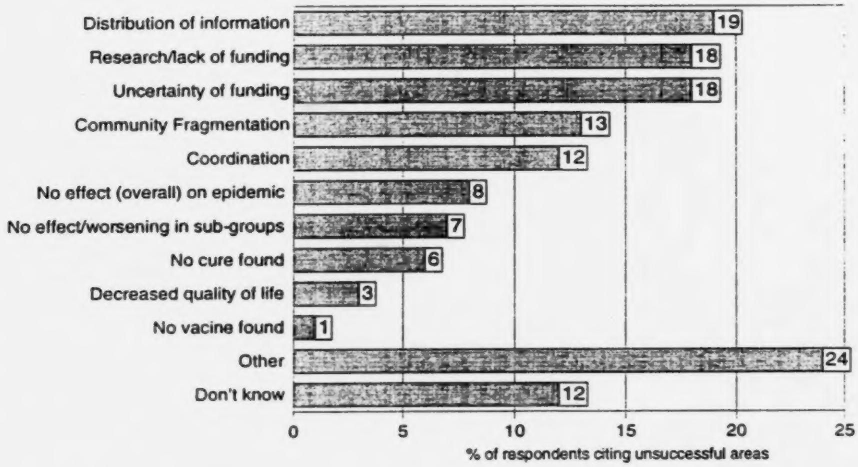
EXHIBIT 5.1
Areas of Success
(All Stakeholders)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=195)

Other successes include the Strategy's impact on stakeholders' ability to conduct the desired range of activities in response to HIV/AIDS and the improved accessibility of the services provided. An overwhelming majority of respondents believe that NAS-II has helped their ability, at least somewhat, to conduct the range of activities that they would like to be doing in response to HIV/AIDS (i.e., 53 per cent indicated that it had helped a great deal, 38 per cent indicated that it had helped somewhat and nine per cent that it had helped not at all). The perceived impact on improved accessibility, although significant, is not quite as substantial; 78 per cent of respondents indicated that NAS-II has helped to make their services more accessible (i.e., 45 per cent indicated that it had helped a great deal, 33 per cent indicated that it had helped somewhat and 13 per cent that it had helped not at all).

EXHIBIT 5.2
Unsuccessful Areas
(All Stakeholders)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=195)

(c) Effectiveness and Impacts

Research and development (R&D) results have a fair amount of impact on stakeholders' programs or services. Over one-half of all respondents indicated that these results had a great deal of impact on their programming (i.e., 61 per cent indicating a four or a five on a five-point scale). Not surprisingly, R&D results had a greater influence on researchers' activities (i.e., 88 per cent indicating a four or a five on a five-point scale). R&D results had the least impact on aboriginal organizations' programs or services (i.e., only 27 per cent indicating a four or a five on a five-point scale).

According to stakeholders, NAS-II has not been particularly effective in terms of achieving two of its objectives. Only one quarter of respondents feel that the National AIDS Strategy has been effective in stopping the spread of HIV/AIDS (i.e., 25 per cent indicating a four or a five on a five-point scale). The Strategy has fared somewhat better with respect to improving care, treatment and support as about one-half feel that it has been effective (i.e., 48 per cent).

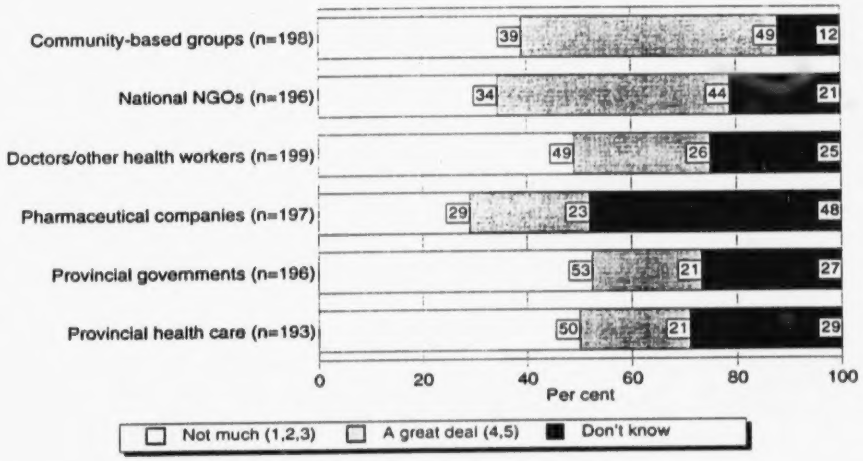
Ethnocultural organizations were twice as likely than other stakeholders to indicate that the Strategy had been effective in stopping the spread of HIV/AIDS (i.e., 52 per cent versus 25 per cent overall). Although ethnocultural organizations were no more likely to indicate that the Strategy had been effective regarding treatment and care, they were more likely to indicate that the Strategy had been extremely effective (i.e., 12 per cent indicating a four on a five-point scale versus five per cent overall).

With respect to the impact of the Strategy on the various players, NAS-II seems to have had the greatest impact on community groups and National NGOs in terms of helping them deal with HIV/AIDS better. Support for the various players appears to be weakest with respect to provincial governments and provincial health care. These findings are displayed in Exhibit 5.3. It should be noted that a fairly large proportion, ranging from 12 to 48 per cent of respondents, were unable to comment on the extent to which the Strategy had helped the various organizations to deal with HIV/AIDS.

(d) Cost-effectiveness

Respondents were divided on the issue of cost-effectiveness; a similar proportion feel that the Strategy has been cost-effective (i.e., 44 per cent) as feel that it has not (i.e., 43 per cent); the remaining 13 per cent were unable to comment on the topic of cost-effectiveness.

EXHIBIT 5.3
Impact of Strategy on Various Organizations
(All Stakeholders)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

3.0 Coordination

Little overlap has been observed by stakeholders among programs and services delivered by federal and provincial governments nor with respect to services delivered by the federal government and NGOs (i.e., 69 per cent indicated for each a one or a two on a five-point scale, where one means no overlap). Of note is that relatively high proportions of professional associations were unable to respond on the issue of overlap (i.e., 24 and 16 per cent for services delivered by federal and provincial governments and services delivered by the federal government and NGOs, respectively).

Although there appears to be little overlap among the different players, coordination appears to be a weak spot in the National Strategy. Only one-quarter of respondents believe that the overall Canadian response to HIV/AIDS is well coordinated (i.e., 26 per cent). In contrast, professional associations and ethnocultural organizations were almost twice as likely to believe that the overall response was well coordinated (i.e., 40 and 46 per cent respectively). Professional associations were also more likely not to respond on this issue (i.e,. 16 per cent).

With respect to information about the National Strategy, 45 per cent of stakeholders rated the availability as very good (i.e., indicating a four or a five on a five-point scale). A slightly higher proportion indicated that it was useful (i.e., 55 per cent). Among stakeholders, professional associations were more likely to indicate very good availability (i.e., 68 per cent versus 43 per cent overall) whereas Aboriginal organizations were less likely to indicate finding the material useful regarding the federal AIDS Strategy; roughly one third of native organizations surveyed found the material useful (i.e., 30 per cent).

4.0 Strategy Components

(a) Clearinghouse

Awareness of the Clearinghouse among stakeholder organizations was high — more than three-quarters of respondents (77 per cent) were aware of the services[1]. Awareness was somewhat higher among community organizations (82 per cent) compared to professional associations (64 per cent). It should be noted that because part of the sampling frame was obtained from lists of groups who have contacted the Clearinghouse, this awareness rate may be somewhat overestimated.

The majority of stakeholder organizations (87 per cent) reported that they had needed the services like those provided by the Clearinghouse. Of those groups who were aware of and had needed the services of the Clearinghouse, 83 per cent had used the Clearinghouse. Satisfaction with the accessibility of information through he Clearinghouse was high — almost three-quarters of respondents reported being satisfied with this aspect of the Clearinghouse. Satisfaction was slightly higher among those who had used the Clearinghouse — 83 per cent of those *versus* those who has used the Clearinghouse *versus* 71 per cent overall.

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[1] Only professional associations and community-based organizations were posed questions regarding the three strategy components (i.e., Clearinghouse, ATIN, Clinical Trials Network).

(b) AIDS Treatment Information Network (ATIN)

Overall, 73 per cent of stakeholder organizations reported a need for information about HIV or AIDS treatments. This was higher among community organizations (80 per cent) compared to professional associations (54 per cent).

Sixty-two per cent of stakeholder groups were aware of CATIE's AIDS Treatment Information Network and just under half (47 per cent) responded that they had needed services like those provided by CATIE's ATIN. Once again, awareness and expressed need for treatment information was higher among community organizations compared to professional associations.

Of those organizations surveyed, about one-half had used CATIE's ATIN to obtain treatment information. Among respondents who had used CATIE's ATIN, three-quarters were satisfied with the accessibility of information through ATIN. Of note is that only 10 per cent of respondents get their information regarding HIV/AIDS treatments from CATIE's ATIN. Not surprisingly, almost two-thirds of community-based organizations and professional associations indicated that they had received information on HIV/AIDS treatments from both local regional NGOs (49 per cent) and large national NGOs (15 per cent). Physicians and health workers, as well as the Clearinghouse, were also frequently cited as sources of information (38 and 30 per cent of respondents respectively).

(c) Clinical Trials Network

About half of the stakeholder groups who responded to the survey (48 per cent) needed information about clinical trials of new HIV/AIDS treatment. This was significantly higher for community organizations (63 per cent) compared to professional associations (12 per cent).

Of those organizations that needed clinical trials information, many acquired this information directly from the Canadian HIV Clinical Trials Network (44 per cent). About one-third (32 per cent) received this information through their physician or health worker.

The majority of stakeholder groups (70 per cent) were aware of the Clinical Trials Network. Of those organizations that stated that they were aware of the CTN, most (62 per cent) stated that their organization or its clients had needed services like those provided by CTN. This was significantly higher among community organizations (70 per cent) compared to 38 per cent of professional associations. Seventy-three per cent of organizations who needed services like those provided by the CTN have had or currently have clients participating in CTN-affiliated clinical trials. Clients had participated in four (researchers) to 14 (community-based organizations) trials on average. Only one professional association reported participating in clinical trials; this organization had participated in 60 trials.

When asked about the extent to which clinical trials were addressing the areas of greatest need, about one-quarter of respondents (28 per cent) did not know; representatives from professional associations were particularly uncertain (50 per cent responded don't know to this question). Forty-three per cent of stakeholder organizations felt clinical trials were addressing needs to a great extent (rated four or five on a five-point scale), 18 per cent responded moderately (three on a five-point scale) and 11 per cent, not a great extent (one or two on a five-point scale).

Sixty-two per cent of the stakeholder groups who responded to the survey believed clinical trials had produced benefits for people living with HIV/AIDS. Three per cent believed clinical trials had not produced any benefits and 23 per cent rated the benefits as moderate; an additional 12 per cent did not know.

Satisfaction with the CTN is quite high, though there is a substantial proportion of respondents (22 per cent) who did not respond or responded don't know to this question (this was higher at 50 per cent among professional associations). Forty-two per cent of respondents reported being satisfied with the activities of the CTN, one in four were moderately satisfied and 11 per cent were not satisfied.

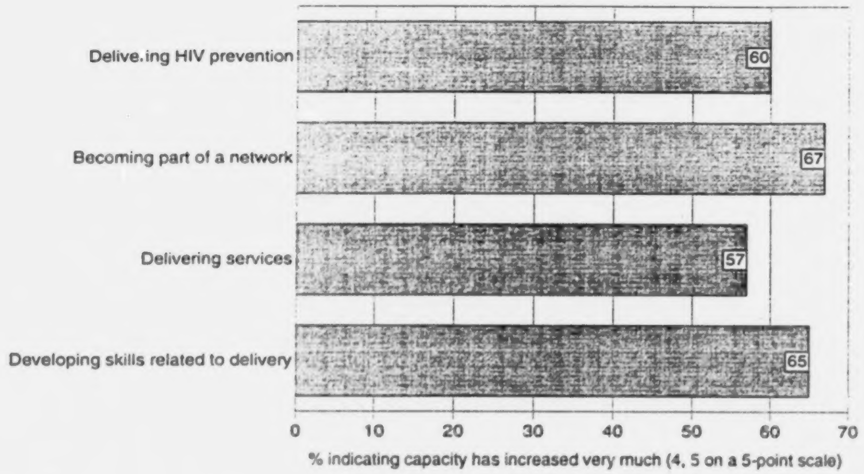
5.0 Group Specific Issues

(a) Community-Based Groups

Community-based groups were asked how much the capacity of their group had increased since 1993 in a number of areas. Just over one-half to two-thirds responded that their capacity had increased a great deal in the various areas (i.e., indicating either a four or a five on a five-point scale). These findings are displayed in Exhibit 5.4.

The greatest improvements in capacity occurred with respect to becoming part of a network of organizations working to stop the spread of HIV (i.e., 67 per cent indicating either a four or a five on a five-point scale). Relatively greater increases were also seen in the capacity to develop the skills of people who deliver services to people living with HIV/AIDS (i.e., 65 per cent) and in the capacity to deliver HIV prevention to vulnerable or high risk individuals (i.e., 60 per cent). Just over one-half of community-based organizations identified an improved capacity to deliver services to people living with HIV/AIDS (i.e., 57 per cent). However, fewer than half (47 per cent) of these groups attributed the federal AIDS Strategy as a significant factor

EXHIBIT 5.4
Increases in Capacity
(Community-Based Groups)



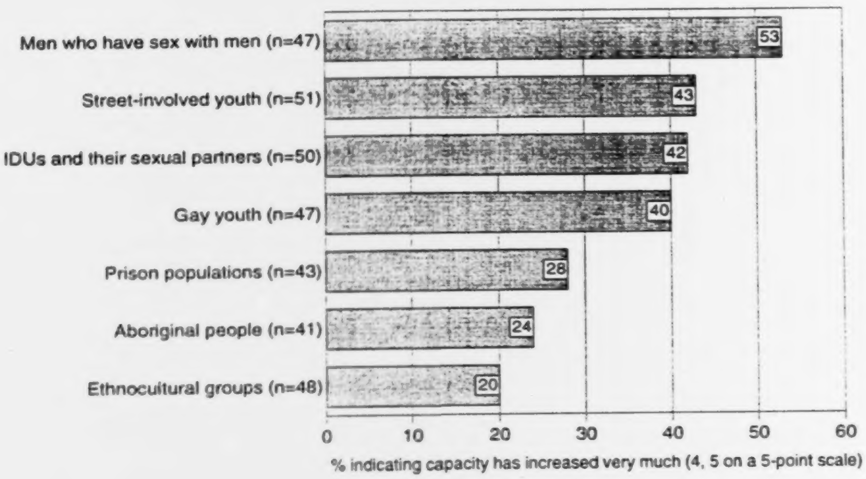
Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=60)

in the increased capacity.

The extent to which capacity had increased since 1993, was explored with community-based groups with respect to four key areas: planning programs; implementing programs; coordinating activities; and mobilizing community resources. Nearly 60 per cent of groups responded that their capacity had increased very much in the first three areas (i.e., 57 per cent in planning programs, 58 per cent in implementing programs, and 60 per cent in coordinating activities). In contrast, only 40 per cent of these groups saw that their capacity to mobilize community resources had improved. As before, fewer than half (49 per cent) of the groups attributed the overall improvements to the federal AIDS Strategy.

Respondents were also asked if their increased capacity had helped them to reach a number of target groups. Responses that increased capacity had helped their efforts to reach target groups very much (i.e., a four or a five on a five-point scale) ranged from a low of 21 per cent to a high of 53 per cent. These figures are presented in Exhibit 5.5 and should be interpreted in light of the fact that different community-based groups will target different groups of individuals.

EXHIBIT 5.5
Increases in Capacity to reach Target Groups
(Community-Based Groups)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

Increased capacity appears to have had the greatest impact on improved efforts for those groups trying to reach men who have sex with men; just over one-half of respondents indicated that increased capacity had helped them reach this target group. An improvement was also noted by about 40 per cent of groups trying to reach youth (43 per cent targeting street-involved youth, 40 per cent targeting gay youth) and 42 per cent of groups trying to reach intravenous drug users (IDU) and their sexual partners. Increased capacity had a limited effect on helping organizations reach prison populations (i.e., 28 per cent), Aboriginal people (i.e., 24 per cent) and ethnocultural groups (i.e., 21 per cent).

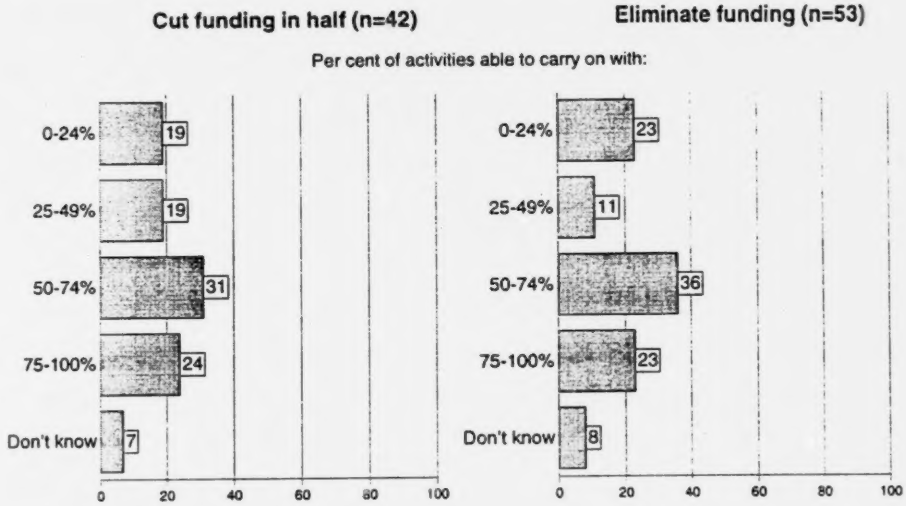
Community-based organizations were asked about the extent to which the federal Strategy had provided them with useful resources and tools to both stop the spread of HIV/AIDS as well as to deliver services to people living with AIDS. A little more than four in ten responded that the federal Strategy had in fact provided them with useful resources and tools to a great extent, with respect to both areas (i.e., 42 per cent and 43 per cent indicating a four or a five on a five-point scale for stopping the spread of HIV/AIDS, and for delivering services respectively).

In view of the fact that resources have become available from more sources since 1993, community-based groups were asked about the proportion of their current activities they would be able to carry on if the federal government were to significantly reduce (almost eliminate) its role and resources. Community organizations would, on average, be able to carry out about one-half of their activities in the absence of federal funding. It should be noted that there was significant variation among groups. Nearly one-quarter (i.e., 23 per cent) responded that they would be able to carry on 75 to 100 percent of their activities, whereas about one-third (i.e., 36 per cent) indicated that they would be able to carry on 50 to 75 per cent of their activities without federal funding. A little over one in ten (i.e., 11 per cent) would be able to carry on 25 to 50 per cent of activities, while just over one-fifth of respondents (i.e., 23 per cent) would be able to carry on less than 25 per cent of their activities. As displayed in Exhibit 5.6, reducing the amount of funding by one-half does not significantly change the proportion of activities that community groups would be able to continue. On average, community-based groups would be able to carry out just under one-half of their activities (i.e., 48 per cent) if federal funding were cut in half.

(b) Professional Associations

Stakeholders were asked a series of questions regarding their involvement in the Strategy, whether their capacity to deliver services had increased, whether this increase could be attributed to the federal Strategy, and if it were

EXHIBIT 5.6
Impact of Funding Cuts on Activities
(Community-Based Groups)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

sustainable in the absence of federal funding.

When asked to what extent NAS-II has engaged their respective professional associations as a partner in the Strategy, less than one-half of stakeholders indicated that their association had been engaged to any great extent (i.e., 40 per cent indicating a four or a five on a five-point scale).

On the issue of increased capacity since 1993, respondents' experiences were divergent. Equal proportions reported little or no increases in capacity as those who reported significant increases in the capacity of the professionals in their respective organizations to deliver services to people living with AIDS/HIV (i.e., 44 per cent responded that capacity had not increased a lot, 44 per cent responded that capacity had increased a great deal, and the remaining 12 per cent did not know). Only one-quarter attributed their increases in capacity to the federal Strategy (i.e., 28 per cent indicating a four or a five on a five-point scale) and few respondents believed that this capacity was sustainable in the face of a significant reduction (i.e., almost elimination) in the federal role and resources (i.e., eight per cent). As a caveat, it should be noted that non-response was fairly high on the two latter issues (i.e., 36 per cent and 20 per cent respectively) and may be indicative of low levels of knowledge regarding the impact of the federal Strategy. Findings should be interpreted accordingly.

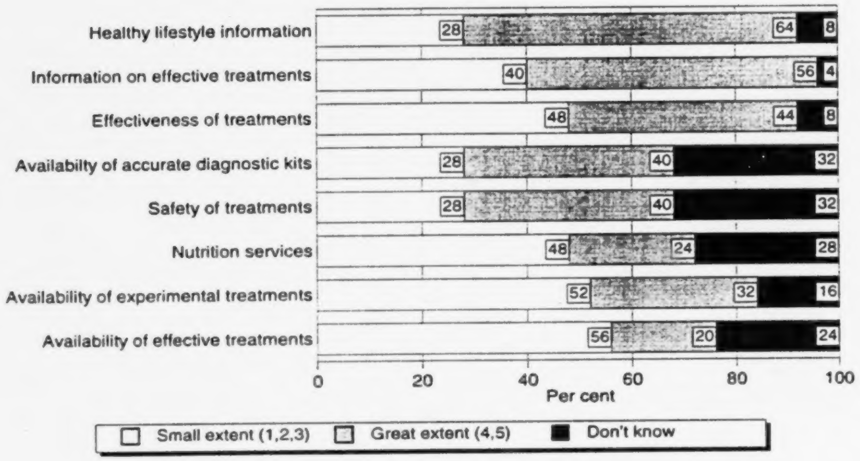
The issue of capacity was explored in more detail with respect to four specific areas. As with service delivery, capacity has similarly not increased with respect to planning programs, implementing programs, mobilizing professional resources, and coordinating activities. Only a minority of stakeholders from professional associations believed that their capacity had increased to plan programs (i.e., 36 per cent), to implement programs (i.e., 28 per cent), to mobilize resources (i.e, 32 per cent) and coordinate activities (i.e,. 44 per cent).

Although professional associations observed only moderate increases in capacity in these four areas, unlike the increases observed in service delivery, a majority responded that these increases were attributable to the existence of the federal Strategy (i.e., 54 per cent). Similarly, a majority believed that the National Strategy has improved services (in general) to people living with HIV/AIDS to a relatively great extent (i.e., 56 per cent indicating a four or a five on a five-point scale).

Professional associations were also asked to comment on how much a number of services, financed by NAS-II, had improved (Exhibit 5.7). The two areas which have seen the greatest improvement are healthy lifestyle information and information about effective treatments. Nearly two-thirds of respondents shared the view that there had been strong improvements in healthy lifestyle information (i.e., 64 per cent indicating a four or a five on a five-point scale). A somewhat lower proportion observed strong improvements in information about effective treatments (i.e., 56 per cent).

In contrast, Professional associations responded that there had been little improvement in the availability of both effective and experimental treatments. Non-response to these items was fairly high, and lower ratings regarding improvement may simply be indicative of a lack of knowledge.

EXHIBIT 5.7
Improvement in Services Financed by Strategy
(Professional Associations)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=25)

In view of the fact that resources have become available from more sources since 1993, professional associations were asked about the proportion of their current activities they would be able to carry on if the federal government were to significantly reduce (almost eliminate) its role and resources. Professional associations would, on average, be able to carry out about 58 per cent of their activities in the absence of federal funding, but with significant variation among the different associations. Less than one-half would be able to continue with 75 to 100 percent of their activities (i.e., 44 per cent). Twelve per cent responded they would be able to carry on 50 to 75 per cent of activities, eight per cent would be able to carry on

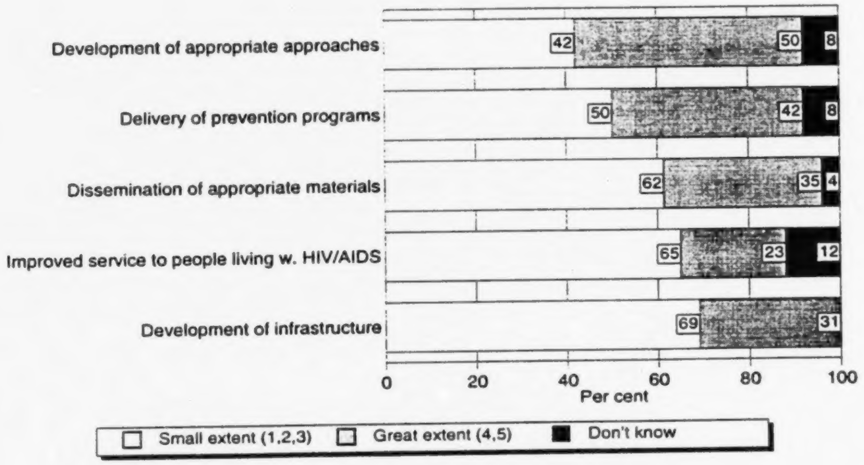
25 to 50 per cent of activities, while 32 per cent responded they would only be able to carry on 0 to 25 per cent.

(c) Ethnocultural Organizations

Ethnocultural organizations were posed a number of questions relating to the federal Strategy. In most of the areas probed, ethnocultural organizations saw the federal Strategy as having only a small impact on their issues or concerns. These findings are displayed in Exhibit 5.8. The Strategy had the least impact in relation to the development of infrastructure, the mobilization of community resources and the dissemination of appropriate information. This may be partially explained by the fact that nearly two-thirds (i.e., 65 per cent) of the organizations perceived that NAS-II had not engaged their respective ethnocultural communities as a partner in the Strategy. In spite of this, one-half of organizations indicated that the federal Strategy had helped communities to develop approaches to dealing with HIV/AIDS to a great extent (i.e., 50 per cent indicating a four or a five on a five-point scale). A similar proportion also attributed increases in their capacity to the federal Strategy (i.e., 48 per cent indicating a four or a five on a five-point scale).

Ethnocultural organizations were also asked how much the capacity of their group had increased since 1993 to plan and implement programs, to coordinate activities and to mobilize community resources. With respect to activities relating to planning and coordination, at least one-half of the organizations reported that their capacity had increased a great deal (i.e., 54 per cent and 50 per cent, respectively, indicating a four or a five on a five-point scale). Somewhat smaller proportions observed significant increases in activities relating to implementing HIV/AIDS programs and mobilizing community resources (i.e., 42 per cent and 31 per cent respectively). About one-half of respondents believed that the federal Strategy had played a significant role in increasing this capacity (i.e., 48 per cent indicating a four or a five on a five-point scale).

EXHIBIT 5.8
Impact of Strategy
(Ethnocultural Organizations)

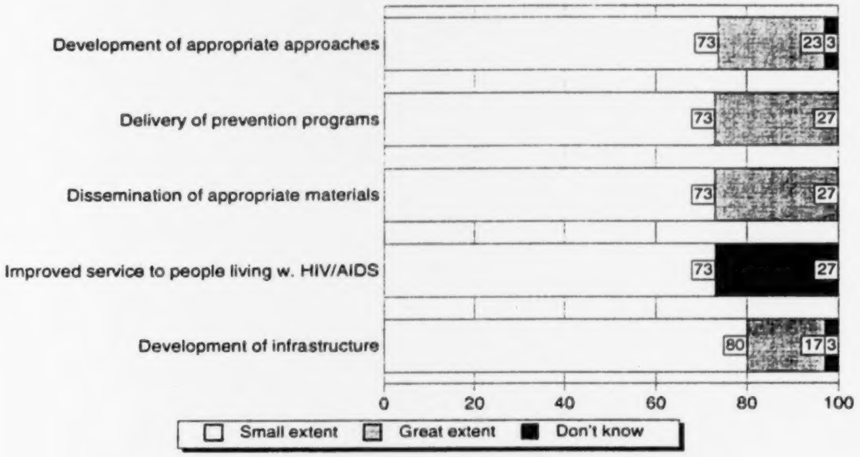


Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=26)

(d) Aboriginal Organizations

Aboriginal organizations were posed a number of questions relating to the impacts of the federal Strategy in a number of areas. Almost seven in ten (i.e., 68 per cent) of these organizations targeted Aboriginal Canadians who live on-reserve. Generally speaking, Aboriginal organizations saw the federal Strategy as having limited impact on their issues or concerns; at least three-quarters of respondents indicated that the Strategy had little or no impact on the areas of interest (Exhibit 5.9). In terms of improving the capacity of their community to respond to the epidemic, eight in ten saw the Strategy as having no impact. This belief is likely to have been reinforced by that the fact that nearly three-quarters of respondents saw themselves excluded in that they did not see any real engagement of the Aboriginal community as a partner in the Strategy (i.e., 73 per cent indicating a one, two or a three on a five-point scale).

EXHIBIT 5.9
Impact of Strategy
(Aboriginal Organizations)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=30)

Aboriginal organizations were also asked how much the capacity of their respective groups had increased since 1993 to plan and implement programs, to coordinate activities and to mobilize community resources. At least two-thirds of the organizations responded that there had been little or no increase in their capacity in the four following areas (i.e., a one, two or three on a five-point scale): 67 per cent indicated little or no impact on coordinating activities, and 70 per cent, 73 per cent and 83 per cent indicated the same for planning HIV/AIDS programs, implementing HIV/AIDS programs, and in mobilizing community resources respectively. Not surprisingly, given previous responses, few respondents saw the federal Strategy as having much impact in those areas where there had been some increases in capacity (i.e., 37 per cent indicating a four or a five on a five-point scale).

The opinions of Aboriginal organizations were also solicited with respect to the Medical Services Branch (MSB) of Health Canada and the AIDS Community Action Program (ACAP). There were no discernible differences between respondents answering with respect to MSB or ACAP. Topics included the usefulness of epidemiological information and effectiveness of prevention activities.

Respondent ratings on these topics were not encouraging. For example, the epidemiological information provided by MSB and ACAP were not perceived to be useful by more than one-half of all Aboriginal organizations (i.e., 57 per cent indicating a one, two or three on a five-point scale). An even greater proportion felt that the HIV/AIDS prevention and education programs of the MSB and ACAP were not at all effective or only moderately effective (i.e., 64 per cent). Awareness of the use of HIV antibody testing services appears to be low; although nearly two-thirds felt that the HIV antibody testing services were not being used all that much; the remaining 36 per cent did not know.

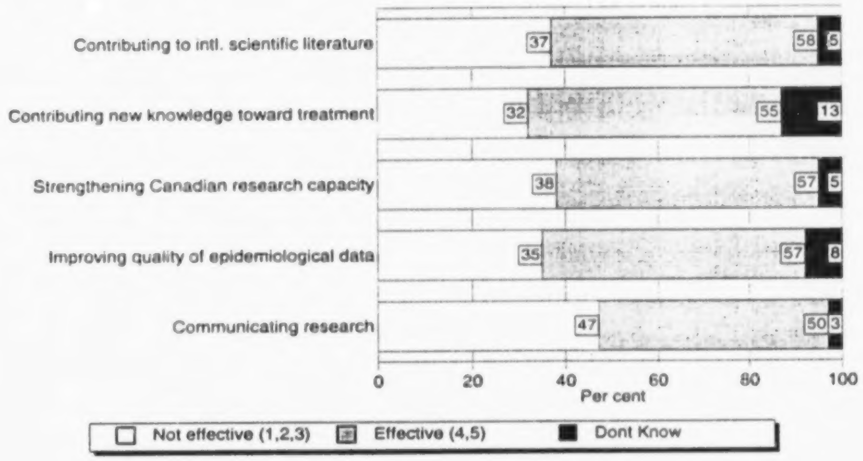
Overall, the Strategy as it has functioned through MSB and ACAP has had little success in Aboriginal communities. Little has been accomplished to stop the spread of HIV among communities (in fact infection rates are increasing). The perceived track records of both MSB and ACAP are similarly discouraging with respect to reaching people in communities and helping to provide services to community members living with HIV/AIDS. More than three quarters of respondents felt that neither MSB nor ACAP have been doing a good job of reaching people in the communities and more than two-thirds felt that they have not helped their respective communities provide services to community members living with HIV/AIDS (i.e., 79 and 68 per cent respectively indicating a one, two or three on a five-point scale).

(e) Researchers

In this section, researchers were posed a series of in-depth questions concerning the overall Canadian research effort. More specifically, respondents were asked to rate the relative effectiveness or ineffectiveness of research and development associated with the national Strategy in a variety of areas. The top five areas in which research and development activities were particularly effective are displayed in Exhibit 5.10 and include the following:

- contributing to the international scientific literature on HIV/AIDS;
- contributing new knowledge toward development of effective drug treatment;
- strengthening the Canadian HIV/AIDS research capacity;
- improving the quality of epidemiological data on HIV/AIDS in Canada; and
- communicating research results.

EXHIBIT 5.10
Five Most Effective Areas
(Researchers — Research and Development)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=60)

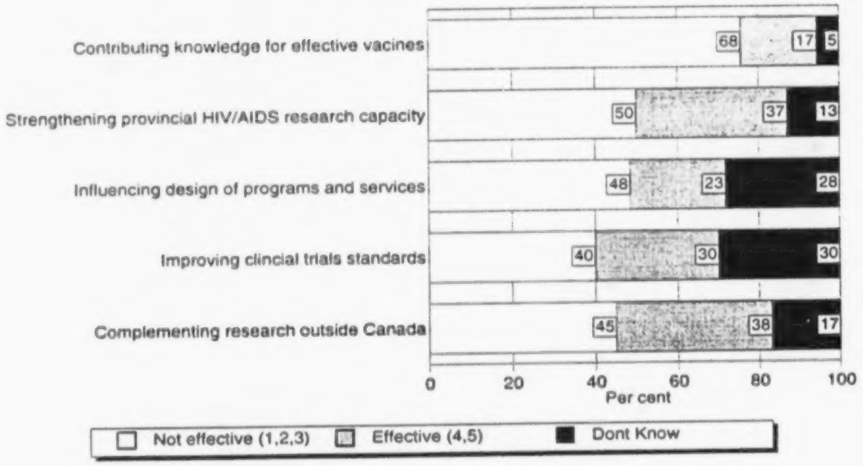
The areas in which research and development activities associated with the national Strategy were least effective are similarly presented in Exhibit 5.11. Least effective areas include the following:

- contributing knowledge toward development of effective vaccines;
- strengthening provincial HIV/AIDS research capacity;
- influencing the design of programs and services;
- improving clinical trials standards; and

- ❑ complementing research done outside Canada.

It should be noted that non-response to these questions was fairly high. High non-response likely reflects a general lack of knowledge among respondents regarding the effectiveness of the research effort. Despite a lack of awareness, consensus is quite high regarding the ineffectiveness of research activities to contribute new knowledge toward the development of effective vaccines. Awareness is lowest regarding the improvement of clinical trials standards and influence of research and development on the design of programs and services. The latter is probably indicative of a lack of communication among researchers and the end-users of their research activities.

EXHIBIT 5.11
Five Least Effective Areas
(Researchers — Research and Development)

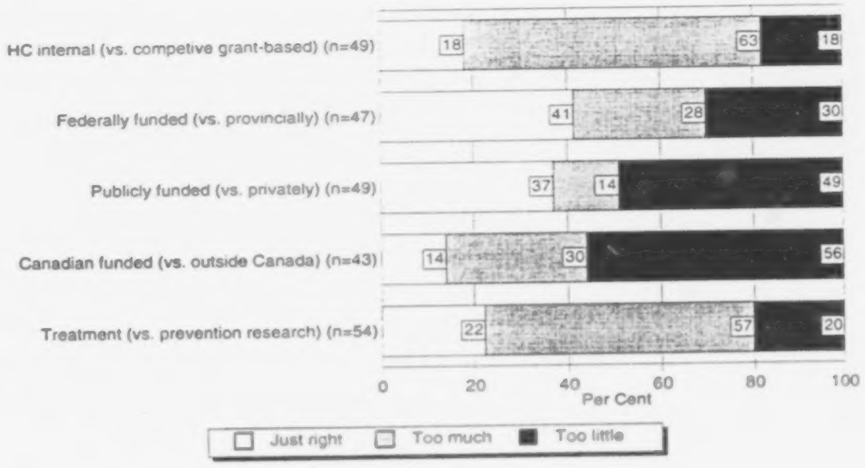


Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=60)

The current balance between several aspects of HIV/AIDS research in Canada was explored with researchers. Pairs of alternative funding mechanisms were presented and respondents were asked whether the balance between the two alternatives was about right, if there was too much or not enough research. As displayed in Exhibit 5.12, researchers generally felt that:

- there was too much internal Health Canada research (and not enough competitive grant-based research);
- too much privately funded (and conversely not enough publicly funded research);
- too much research funded from outside Canada (and not enough funded from within Canada); and
- not enough research on prevention (and conversely, too much on treatment research).

EXHIBIT 5.12
Balance Among HIV/AIDS Research Alternatives
(Researchers)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

In addition to the issue of the balance of research activities, survey respondents were also asked a number of questions concerning Canada's two principal granting agencies, the National Health Research and Development Program (NHRDP) and the Medical Research Council (MRC). Respondents were asked the extent to which NHRDP's AIDS research grant programs have generated new knowledge about such issues as HIV pathogenesis (basic disease processes), education and prevention (transmission of the disease) and care, treatment and support. Respondents were of the view that NHRDP's AIDS research programs had generated new knowledge about HIV pathogenesis (i.e., 50 per cent indicating a four or a five on a five-point scale), but were less convinced of its ability to generate new knowledge about education and prevention (i.e., 36 per cent) or care, treatment and support (i.e, 30 per cent).

On the subject of MRC's programs in generating knowledge relevant to both education and prevention services, as well as care, treatment and support services, a majority of respondents (i.e., 62 per cent and 64 per cent indicating a one, two or a three on a five-point scale, respectively) were of the view that the MRC's programs were only marginally effective in generating new knowledge.

Respondents held similar views regarding the effectiveness of NHRDP/MRC's joint programs' contribution to the development of vaccines, drugs or therapies, a majority of respondents were of the view that the joint programs have had little or no impact on the generation of new knowledge (i.e., 52 per cent indicating a one, two or a three on a five-point scale).

Lastly, respondents were asked the extent to which both the NHRDP's and the MRC's Career and Training Awards had increased Canadian capacity for HIV/AIDS research. Two thirds of respondents felt that the NHRDP's Awards had significantly increased Canadian capacity for HIV/AIDS research, whereas only a fraction of respondents (i.e., 26 per cent) felt that the MRC Career and Training Awards had achieved the same result.

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 10:
Survey of People Living with HIV/AIDS

September 2, 1997

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TABLE OF CONTENTS

1.0 Methodology 1
  1.1 Sample Characteristics 3

2.0 Survey Findings 4
  2.1 Supports Received by People Living With HIV/AIDS 4
  2.2 Access to Information and Treatment 5
  2.3 Views of People Living With HIV/AIDS on the National AIDS Strategy 7
  2.4 Other Comments 9

Evaluation of the National AIDS Strategy — Phase II

TECHNICAL REPORT No. 10: Survey of People Living with HIV/AIDS

This technical report presents the results of the survey of people living with HIV/AIDS. In the analyses presented below, respondents were categorized according to the date of their diagnosis with HIV or AIDS, with those diagnosed prior to the beginning of NAS-II (1993) compared to those diagnosed later. Of the respondents, 111 were diagnosed prior to 1993 and 77 were diagnosed in 1993 or later.

1.0 Methodology

In order to preserve confidentiality and in recognition that members of several of the HIV/AIDS vulnerable groups are marginalized and difficult to reach, this survey was conducted through anonymous questionnaires distributed through two methods. First, respondents in the Stakeholder Surveys of HIV/AIDS NGO's, ethnocultural and aboriginal groups were asked to distribute questionnaires to users or clients of their services. Fifty-nine of 60 organizations accepted, and a total of 1,300 questionnaires were distributed to them. The second source of respondents came from patients of clinicians listed in the Canadian HIV/AIDS Physicians Directory. Twenty-five randomly selected physicians accepted to distribute questionnaires to their patients, and a total of 600 questionnaires were distributed to them. In both cases, the questionnaire was accompanied by a stamped, addressed envelope, and returned directly and anonymously to the consultant. The survey instrument was reviewed through Health Canada's Information Collection Approval Process and its Human Studies Committee.

A total of 229 completed questionnaires were returned, 200 from the distribution through non-governmental organizations (NGO's) and 29 through treating physicians. Of these, 173 questionnaires were English and 56 were French.

A few differences in responses were noted with respect to the method by which questionnaires were distributed to respondents. Most of the differences observed were not surprising, given the nature of the distribution method. First, respondents who had received their questionnaires from NGO's were more likely to have indicated NGO's as a source of help (i.e., 29 per cent versus zero per cent of respondents who received their questionnaire from a treating physician).

Second, respondents who received their questionnaire from a treating physician found it easier to obtain information about treatments (79 per cent found it quite or very easy versus 54 per cent of those from the NGO distribution method). They have also participated in more research studies and have found it easier to participate in these studies. Of those who wanted to participate in a research study, 69 per cent who received their questionnaire from a physician had participated in a study versus 37 per cent of those who received their questionnaire from an NGO. As well, 51 per cent found it quite or very easy to participate versus 23 per cent of those from the NGO distribution method.

Finally, respondents who received their questionnaires from treating physicians were more likely to live in a big city (i.e., 66 per cent versus 39 per cent of the NGO distribution method) and to have contracted HIV/AIDS prior to 1993 (i.e., 79 per cent versus 58 per cent of the NGO distribution method).

1.1 Sample Characteristics

Because of the need to preserve anonymity, it is very difficult to ascertain the representativeness of this sample in terms of all Canadians living with HIV/AIDS. Some sociodemographic information was obtained from respondents, however, and the characteristics of the sample appear to be similar to those of the population of people living with HIV/AIDS (e.g., in terms of the percentage of men and the regional distribution of HIV/AIDS cases) so some generalization may be possible.

Sixty-eight per cent of respondents were 35 years or older with only four per cent being less than 24 years of age. Differences in the ages of respondents were noted when the responses were categorized according to when respondents were diagnosed with HIV. Respondents diagnosed with HIV as of 1993 were more likely to be less than 24 years of age than those diagnosed prior to 1993 (eight per cent compared to one per cent). Eighty-two per cent of respondents were male. Respondents diagnosed with HIV as of 1993 were more likely to be female than those diagnosed prior to 1993 (24 per cent versus 14 per cent). This finding, however, is not statistically significant. One hundred per cent of respondents were HIV positive or diagnosed with AIDS and 34 per cent are close to someone with HIV or AIDS.

Forty-six per cent of respondents live in a smaller city and 42 per cent live in a larger urban centre. These proportions are the same regardless of whether respondents were diagnosed prior to 1993 or as of 1993. The majority of respondents live in Quebec (26 per cent), British Columbia (21 per cent) or Ontario (23 per cent). Eighteen per cent live in the Prairies and nine per cent live in Atlantic Canada. Zero per cent live in either the Northwest Territories or the Yukon.

2.0 Survey Findings

2.1 Supports Received by People Living With HIV/AIDS

Respondents to the survey of people living with HIV/AIDS were asked about the kinds of support they are receiving. This is a means of assessing how well the Strategy is actually reaching people living with HIV/AIDS. The primary kind of help being received by respondents is informational (83 per cent), followed by treatment (80 per cent) and moral support (70 per cent). Forty-eight per cent of respondents indicated receiving financial support with 20 per cent indicating receiving help with living arrangements. Only one per cent of respondents indicated not receiving any help at all. Eleven per cent of respondents indicated receiving other types of help. These other types of help varied significantly with no one type being cited more than two times. Examples of these include: medical coverage, help with food, self-help and skills training.

Friends and family were identified by just over a third of respondents (39 per cent) as being the primary source of help. This is followed by volunteer or community groups (24 per cent) and doctors (15 per cent). Eight per cent of respondents indicated other sources as being their primary source of help. The most often noted sources were the respondent themselves and local AIDS committees and service organizations. Both respondents diagnosed with HIV prior to 1993 and those diagnosed as of 1993, indicated family and friends, volunteer or community groups and doctors as being their primary sources of help.

Forty per cent of respondents feel they are being helped "a lot" or "very much" in living with HIV/AIDS, with 34 per cent feeling they are receiving some help. At the opposite end of the scale, 17 per cent feel they are receiving "little" help and seven per cent feel they are receiving almost no help at all. These findings hold true regardless of whether respondents were diagnosed with HIV prior to 1993 or as of 1993.

When asked what kind of help they need more of, 45 per cent indicated financial support. Following at a distant second is the need for more moral support (17 per cent). Thirteen per cent of respondents indicated that they need more treatment support and 12 per cent indicated that they did not need more help. Respondents diagnosed with HIV as of 1993 were slightly more likely to indicate that they need more financial support (48 per cent) than those diagnosed prior to 1993 (42 per cent). Those diagnosed as of 1993 were also slightly more likely to feel a need for more moral support than those diagnosed prior to 1993 (20 per cent compared to 15 per cent) and less of a need for treatment (10 per cent versus 15 per cent). These differences, however, are not statistically significant.

2.2 Access to Information and Treatment

Based on their experience, respondents tended to feel that the services in their region for people living with HIV/AIDS were somewhat organized (36 per cent) to quite organized (35 per cent). Seventeen per cent were of the opinion that the services in their region are very well organized. At the other end of the spectrum, only five per cent feel that services in their region are not at all organized. This perception of how well-organized services within the regions are is consistent regardless of whether respondents were diagnosed with HIV prior to 1993 or as of 1993.

Overall, respondents feel that it is relatively easy to get the information they need. Thirty-six per cent indicated it is very easy, 31 per cent feel it is quite easy, and 28 per cent find getting information not too hard. Although not statistically significant, responses changed depending on when respondents were diagnosed. Respondents diagnosed prior to 1993 were slightly less likely to think access to information was quite easy than those diagnosed with HIV as of 1993 (30 per cent compared to 33 per cent). On the other hand, those having been diagnosed as of 1993 were less likely to think access to information was very easy (32 per cent) than those diagnosed prior to 1993 (37 per cent).

The perception of respondents about the ease of finding information shifts somewhat when speaking specifically about accessing treatment information. Twenty-five per cent of respondents feel that it is very easy to get information on treatments, with 32 per cent indicating it is quite easy and 31 per cent believing it to be not too hard. Ten per cent indicated that it is quite hard to get the information they need about treatments. Statistically significant differences were noted when responses were broken down according to whether respondents had been diagnosed with HIV prior to 1993 or as of 1993 ($p=.01$). Forty-two per cent of respondents diagnosed as of 1993 feel that it is not too hard to access information on treatment compared to 24 per cent of those diagnosed prior to 1993. On the other hand, 30 per cent of respondents having been diagnosed prior to 1993 thought access to treatment information was very easy compared to 14 per cent of those diagnosed as of 1993.

Sixty-two per cent of respondents indicated from where they received their information. For respondents, there are two main sources of information: the health care community (i.e., doctors, hospitals, clinics) and community AIDS organizations and committees. CATIE or the Network was also cited as a distant third.

In terms of the treatment available for people with HIV/AIDS, based on their own experience, the majority of respondents rated it either okay (38 per cent) or good (32 per cent). Sixteen per cent feel it was very good and 12 per cent feel it was poor. Generally speaking, respondents diagnosed with HIV as of 1993 were more positive about the treatment available than those having been diagnosed prior to 1993. Those diagnosed as of 1993 were much more likely to feel that the treatment available for people living with HIV/AIDS was good than were those diagnosed prior to 1993 (42 per cent versus 27 per cent) and were also slightly more likely to feel it is very good (18 per cent versus 14 percent). Not surprisingly, respondents diagnosed prior to 1993 were more likely to rate the treatment available as okay than were those that have been diagnosed as of 1993 (43 per cent versus 29 per cent). These differences, however, are not statistically significant.

The majority of respondents (74 per cent) indicated that they have wanted to be in a research study with new treatments with 42 per cent saying they have been and 32 per cent indicating they have not. Differences were found when responses were broken down according to whether respondents had been diagnosed with HIV prior to 1993 or as of 1993. Fifty-four per cent of those diagnosed prior to 1993 have participated in a research study compared to 25 per cent of those diagnosed as of 1993. Also, 35 per cent of those diagnosed as of 1993 indicated never having wanted to participate compared to 17 per cent of those diagnosed prior to 1993.

For those respondents either having participated in a research study or wanting to participate, it is their perception that it is not overly easy to get into a research study with new treatments. Twenty-three per cent feel it is not too hard, with 19 per cent thinking it is quite hard and 16 per cent feeling it is very hard. Only 10 per cent thought it was very easy and 14 per cent didn't know. There were no statistically significant differences when responses were categorized according to when respondents had been diagnosed with HIV.

2.3 Views of People Living With HIV/AIDS on the National AIDS Strategy

Respondents to the survey of people living with HIV/AIDS were asked to provide their views on the national effort. When asked how much they feel is being done in Canada to help those living with HIV/AIDS, over half feel that "some" is being done (59 per cent) with 17 per cent being of the opinion that a lot is being done. Only five per cent are of the opinion that everything possible is being done. Seventeen per cent feel that nothing is being done.

Thirty-eight per cent of respondents to the survey of people living with HIV/AIDS feel that research has helped people living with HIV/AIDS a lot, with 17 per cent feeling that it has helped very much. Thirty-six per cent feel has been some help. Only eight per cent feel that research has helped not at all or almost not at all. These findings hold true regardless of whether respondents were diagnosed with HIV prior to 1993 or as of 1993.

Seventy-nine per cent of respondents had heard of the National AIDS Strategy. There is a difference when these findings are categorized according to when respondents were diagnosed with HIV. Respondents diagnosed prior to 1993 were more likely to have heard of the National AIDS Strategy (85 per cent) than were those diagnosed as of 1993 (71 per cent).

Forty-four per cent of respondents have heard of the National AIDS Clearinghouse and 60 per cent of those who have heard of it have used it. Of the respondents who have used it, 55 per cent feel it was very useful and 36 per cent feel it was somewhat useful. Differences were noted when responses were broken down according to whether respondents had been diagnosed prior to 1993 or as of 1993. Fifty-one per cent of respondents who had been diagnosed prior to 1993 had heard of the Clearinghouse compared to only 35 per cent of those diagnosed as of 1993. As well, respondents who had received their questionnaire from an NGO were more likely to have heard of the Clearinghouse than those who had received their questionnaire from a physician (i.e., 48 and 14 per cent, respectively). In terms of use and helpfulness of the information, there were no statistically significant differences.

Fifty-seven per cent of respondents have heard of CATIE's AIDS Treatment Information Network and 61 per cent of those who have heard of it have used it. Of the 71 respondents who have used it, 64 per cent feel it was very helpful and 31 per cent feel it was somewhat helpful. Although not statistically significant, differences in responses were found when examined by when respondents were diagnosed with HIV. Respondents diagnosed prior to 1993 were more likely to have heard of CATIE's ATIN (64 per cent) than were those diagnosed as of 1993 (46 per cent). As well, respondents who had received their questionnaire from an NGO were more likely to have heard of the CATIE's ATIN than those who had received their questionnaire from a physician (i.e., 60 and 41 per cent, respectively). In terms of use and helpfulness of the information, there were also no statistically significant differences.

Fifty-five per cent of respondents had heard of the Clinical Trials Network (CTN) and 25 per cent of those have participated in its activities. Of the 30 respondents who had participated in its activities, 46 per cent feel that it had helped some and 34 per cent feel it helped a lot. Nine per cent feel it was almost no help at all and seven per cent feel it was not at all helpful. Differences were noted when responses were broken down according to whether respondents had been diagnosed prior to 1993 or as of 1993. Sixty-one per cent of respondents who had been diagnosed prior to 1993 had heard of the CTN compared to 45 per cent of those diagnosed as of 1993. As well, respondents who had received their questionnaire from an NGO were more likely to have heard of the CTN than those who had received their questionnaire from a physician (i.e., 58 and 41 per cent, respectively). In terms of use and helpfulness of the information, there were no statistically significant differences.

2.4 Other Comments

A number of other comments were also provided by respondents. The most common ones noted were: renew the Strategy, increase funding for research (including for treatment and a cure) and increase assistance for individuals (e.g., financial, moral, retraining). Other comments include: provide more funding to AIDS service organizations, increase funding for education and prevention, increase funding to smaller and rural communities and their agencies, and all types of information for special groups (e.g., First Nations, women).

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 11:
Lessons Learned Case Studies

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TABLE OF CONTENTS

1. ConsAIDS Project 1
2. Projet Accès 8
3. Vancouver Lymphadenopathy-AIDS Study (VLAS) 10
4. Vaccine Development Research Program 15
5. Street Connections 19
6. Fourth Canadian Aboriginal Conference on HIV/AIDS and Related Issues 27
7. Healthy Choices Project 33

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 11: Lessons Learned Case Studies

1. ConsAIDS Project

(a) Project Description

The Cons AIDS Network (C.A.N.) Project was a pilot project which involved inmate peer education and support regarding HIV/AIDS. The pilot was originally recommended by the Expert Committee on AIDS in Prisons. The peer counselling approach was chosen due to the sensitive nature of the topic matter and the fact that inmates are both more familiar with the risky activities that occur within a prison and better able to communicate with inmates. The philosophy of the exercise was focused on empowering inmates to take control of their own health and well-being.

First, a number of inmates would receive information about HIV/AIDS and training in peer counselling, education and support activities. These individuals would then go into the prison population and encourage the inmates to practice safe sex, to properly clean needles, and generally raise awareness about HIV/AIDS and risky activities. The ultimate goals of the project were to:

- ☐ increase knowledge;
- ☐ change attitudes and behaviours; and
- ☐ decrease the transmission of HIV/AIDS and other diseases (e.g., Hepatitis).

In terms of the pilot as a research project, another goal was to develop, implement and evaluate a sustainable model of peer counselling.

The mission of the project was said to correspond to that of Correctional Services Canada (CSC): to rehabilitate an inmate, to prevent harm from coming to them (i.e., prevent them from contracting HIV/AIDS), and to make them contributing members of society when they get out (i.e., avoid spreading the disease).

The pilot project was undertaken at Dorchester Penitentiary, a medium security federal prison in New Brunswick. This venue was chosen mainly because of its proximity to the staff at AIDS New Brunswick. AIDS New Brunswick submitted a proposal to undertake the pilot study in May of 1994. The staff at AIDS New Brunswick were considered to be experienced because they had been entering the prison since about 1992/1993, providing inmates and staff with information on HIV/AIDS. The workers also provided some counselling and support help as well. Furthermore, the staff had previously trained nurses to provide education and support regarding HIV/AIDS.

The project started in February, 1996. There were a number of different partners that worked with CSC to implement the pilot. In particular, funding for the contract to set up the pilot was received from Health Canada via the National AIDS Strategy, Phase II, AIDS Education and Prevention Unit. Both key informants believed that without the financial assistance of Health Canada, this pilot project would never have happened.

Two staff members from AIDS New Brunswick were involved in providing training and advice, and the development of a facilitation manual that would assist with implementation in other venues. It was decided that ten inmates would receive training; two of whom would be coordinators. The training was on-site and lasted 120 hours, implemented over the course of four weeks. Those inmates chosen as coordinators received an additional five weeks of one-on-one support and training. As well, the trainer made periodic visits to the penitentiary to answer any questions, etc..

Once fully trained, activities undertaken by the peer counsellors included:

- distributing condoms and information (pamphlets, books, audiovisual materials as well as verbally);
- one-on-one prevention and support;
- group information and interactive workshops;
- production of a monthly newsletter;
- attendance of a support group for prisoners with HIV/AIDS (Prisoners with AIDS — PWA);
- written correspondence with HIV-positive prisoners in other Atlantic Region institutions; and
- staffing an office at the penitentiary 36 hours per week.

According to one key informant, this pilot project "is the first one done in the world, from what we've heard." In any case, it has brought international attention with enquiries coming from the U.S. and as far away as Argentina. Specific aspects that have made this project innovative (according to key informants) include:

- ☐ the focus on empowering inmates to take control of their own health (compared to previous passive methods such as information sessions and videos);
- ☐ the comprehensiveness of the training program (120 hours over 4 weeks);
- ☐ the evaluation component which implemented pre- and post- KAB (knowledge, attitudes and behaviours) questionnaires;
- ☐ having two inmates in paid positions for HIV/AIDS information and support; and
- ☐ the effective implementation of peer counselling in a prison setting.

Partnerships developed for the pilot project were many, including CSC, Health Canada and AIDS New Brunswick. The National Advisory Committee included members from CSC, Health Canada, the John Howard Society, other service organizations and inmates. As well, there was a Sub-Committee developed at Dorchester which had members from the staff, administration and inmate population of the prison. Staff from Brock University conducted the evaluation component and specific community organizations that were involved include AIDS New Brunswick, AIDS/SIDA Moncton, Hepatitis Society, PASAN, Prisoners Legal Aid Network and CPHA.

While Health Canada served primarily as a funding partner, many resources funded by NAS were utilized in the pilot. For example, *Virus in the Steel* and *Finding Out What You Need to Know* were both used. As well, the National AIDS Clearinghouse was consulted to conduct a literature search and to obtain a number of materials and videos. Finally, most of the members on the Advisory Committee were in some way linked to NAS-II (the organizations represented on the committee received funding, or were themselves from Health Canada — ACTP).

Besides the resources funded by NAS-II, the only other source of information was a training manual from a peer education program implemented in Australia. While this program had a different focus and client group, the manual was considered useful in terms of logistics.

(b) Effectiveness and Lessons Learned

Some of the barriers and challenges that were encountered while setting up the pilot included:

- ❑ ignorance and prejudice of both staff and inmates (especially high among the guards);
- ❑ relaying the information in language that was easily understood by inmates (many inmates did not have beyond a grade eight education);
- ❑ gaining the trust of the inmates (i.e., to assure them that they would not be reported); and
- ❑ the stigma attached to HIV/AIDS-related activities made it very hard to attract inmates to the training sessions.

While education levels have increased at the prison, organizers are still having a difficult time encouraging inmates to volunteer for the second round of training (five of the original ten have been paroled and have therefore left the project). One remaining challenge is that of sustainability (in terms of funding as well as in terms of keeping trainees motivated; attrition is also a factor).

Strengths identified by key informants include:

- ❑ development of a very comprehensive training program;
- ❑ worked with other departments and thus developed a number of interdepartmental relationships;
- ❑ informal approach encouraged inmates to participate;

- empowering inmates to take control of their own health;
- the significant influence on the inmates (the pre- and post- KAB results presented in the evaluation report show that more than three-quarters of the inmates who completed both the pre- and post-test (75.8 per cent) reported that their knowledge about HIV/AIDS and other communicable diseases had increased since the beginning of the C.A.N. Project);
- the inherent strengths of peer counselling enabled communication with the target population (inmates) by making the education less driven by rules and by allowing the educators (inmates) to use language understood by their fellow inmates; and
- comprehensive pilot evaluation study.

Both key informants also expressed how pleased they were with the two coordinators in terms of their dedication to the project as well as their compassion.

One particular suggestion for improvement would include the increased involvement of Health Centre nurses as the project does not currently have a nurse dedicated to it. As well, it was mentioned that it would have been beneficial if there had been a method in place to measure the long term impacts of the pilot (the post-test was implemented three months after the end of the pilot).

When asked specifically about lessons learned, key informant had the following comments:

- "peer counselling works!";
- it is important to recruit a cross-section of inmates (race, sexual orientation, culture) to receive training; and
- a mechanism should have been put in place to provide periodic training to the peer educators.

Many impacts were realized from the pilot project. For example, awareness of the disease and its transmission has been increased. Also, there are more inmates coming forward to be tested and many dropping in to the office for information. Awareness of the project has also spread as there have been a number of inmates of other penitentiaries requesting transfers to Dorchester because of the HIV/AIDS information and support services.

According to the evaluation report (November, 1996), "the data ... indicate that inmates can effectively provide education and support to their peers." The evaluation continues to list the results of the pilot:

- ❑ increased knowledge scores (mean knowledge scores (on 41 HIV/AIDS-related items) were significantly higher for post-test respondents: an average post-test score of 73.7 per cent versus 62.9 per cent for pre-test respondents);
- ❑ enhanced attitudes toward prisoners with HIV/AIDS (the greatest improvement in attitude was in response to the statement: "Sharing a cell with an inmate who has HIV/AIDS would not bother me"; compared to 51.8 per cent agreeing in the pre-test, a full 67.7 per cent agreed in the post-test);
- ❑ increased intentions to engage in HIV-related risk reduction behaviours (27 per cent of post-test respondents had intentions to modify their sexual or needle use behaviour in some way in the upcoming four weeks, compared to only 14 per cent of respondents in the pre-test); and
- ❑ reporting of safer behaviour (37.3 per cent indicated that their sexual or needle use behaviours had become safer since the onset of the C.A.N. Project).

This project is currently past the pilot stage and is ongoing. However, it is operating as a "cut down" version due to the lack of funding (for example, the AIDS New Brunswick trainer is only able to provide training with no post-program support). At the time of this case study investigation, new inmates were being sought to receive training (a number of inmates were paroled and therefore left the prison). The training program being offered is an abbreviated version of the original and trainees will not receive ongoing support from AIDS New Brunswick.

2. Projet Accès

In large metropolitan areas such as Montreal, there are many public and non-government structures involved in treatment, care and support of people living with HIV/AIDS. It appears that in many cases, the global effectiveness of the actions of these groups is limited by a lack of communication and coordination between the different partners. The lack of coordination can occur between organizations and groups, as well as within organizations, that is, between its own subunits. This diagnosis motivated the federal government[1] to invite the Centre québécois de coordination sur le sida (CQCS) to set up a new intervention model that would improve coordination between local partners as well as the living conditions for people living with HIV/AIDS in the central Montreal area.

(a) Project Description

The project, entitled *Projet Accès*, took place between 1991 and 1995[2]. The National AIDS Strategy supported this project through direct funding, $1.9 million over a period of four years, and by providing expertise and documentation. The objectives of *Projet Accès* were:

- ☐ to coordinate and integrate the actions of the organizations and groups involved in treatment, care and support for people with HIV/AIDS, namely the hospitals, the local community service centres (Centre locaux de services communautaires), and the community groups;
- ☐ to provide training to health professionals, especially with regards to palliative care; and

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[1] Which also funded a similar project in Edmonton.

[2] This case study is based on interviews and an evaluation report (Germain, C., Fillion, J., *Projet Accès; Rapport final*, novembre 1995).

- ❑ to increase the awareness and knowledge of palliative care of people living with HIV, and of people living close to them.

The project was based on two assumptions. First, it assumed that the different elements of the treatment, care and support system are interdependent, but not necessarily well-coordinated. Second, it relies on the belief that the person living with HIV/AIDS wants to choose and coordinate the services he or she needs, for as long as he or she can. *Projet Accès* therefore promoted a self-help approach and created tools that would be used by people living with AIDS.

The CQCS implemented an intervention team to lead a diagnosis of the situation and implement new practises. The team established a coordination table where senior management members of the health and community organizations in Montreal met on a regular basis. The mission of this group of people was to identify needs and resources; analyze the weaknesses of local care and treatment systems; establish new services according to need; identify training needs for professionals; and plan common actions for palliative care. The intervention team also coordinated the development of a new self-help approach for the individual, called the *Plan de services individualisés*. To implement this approach, workshops and training sessions were organized for professionals, a directory of resources and services was printed, and for the people living with HIV/AIDS, a guide was produced to help the individual cope with his or her situation, namely through self-help.

(b) Effectiveness and Lessons Learned

The effectiveness of the project varied from one component to another. The coordination table component was mostly effective at finding solutions that could be applied by a specific group or institution. Solutions that involved the coordination of many groups or institutions were less effective, however. This was thought to be primarily because it proved to be very difficult to coordinate actions of groups and institutions that are complex, rigid and very different. Although the coordination table is still on-going, it has not been successful at implementing changes at the inter-organizational level, where the coordination efforts proved to be less effective, especially when the recommendations involved structural changes.

According to the evaluation report, the self-help booklet, a major component of the project, had positive psycho-social impacts on those who used it. Interview respondents noted that the booklet was widely disseminated and proved to be very helpful for its users. The training sessions for the professionals were also successful in raising awareness of the needs of their clientele and the resources available, and in improving the coordination of the care and treatment services.

Thus, the lessons learned from this experience may be summarized by the following two statements:

- ❑ a coordinated effort involving participants from many local organizations to improve self-help and palliative care for people living with HIV/AIDS is possible and can be effective; and
- ❑ the coordination of many local health institutions and community groups can, however, be a difficult task. A more coordinated effort can be partly achieved by providing training sessions to local professionais involved with people living with HIV/AIDS. Structural changes are somewhat more difficult to implement.

3. Vancouver Lymphadenopathy-AIDS Study (VLAS)

(a) Project Description

The Vancouver Lymphadenopathy-AIDS Study (VLAS) is a research study funded by the National Health Research and Development Program. The study is based on a cohort or longitudinal methodology. The general objective of the research "has been to contribute to our understanding of the natural history of HIV infection, of the epidemiology of HIV and its modes of transmission and of the etiology of AIDS and its related clinical outcomes.

The initiation and design of the study has its historical roots in the observations of a group of family physicians in Vancouver in the early 1980s. These physicians, all with practices composed of a significant proportion of homosexual men, began noting cases of lymphadenopathy among their gay patients. These doctors launched a rudimentary study of affected patients. This initiative later became a full-fledged cohort study with funding from the National Health Research and Development and Program (NHRDP) and a small grant from the province of British Columbia. (Since that time the NHRDP has been the sole funder of the research.)

In total, about 1,000 homosexual men were recruited into the study; 729 between 1982 and 1984 and 271 men between 1986 and 1987. More recently, in 1993 a new vanguard cohort was added which involved the recruitment of 1,000 young gay men. All were recruited from general practices in central Vancouver.

The research involves regular visits with subjects who are asked to complete a self-administered questionnaire which gathers information on their activities and sexual and health practices including risk behaviours and treatments, a physical examination and blood samples from which immunologic and HIV antibody testing is done. Visits were conducted every six months up to September 1996 and annually after that.

The study is unique in that it was one of the first cohort studies which was established to study the disease. In 1982 when the research began, the human immunodeficiency virus had not yet been identified. There was little information about the causes of the illnesses which were being experienced by gay men, its prevalence or source of transmission.

The cohort study provides opportunities to inform public health policy and to advance HIV/AIDS research. This information can be derived from study of two groups: HIV negative and HIV positive subjects. First, the study of subjects who are HIV positive, including those who were HIV positive at the outset of the study or who became infected under observation (over 200) provides valuable information on the natural history or progression of the disease and the effectiveness of treatments. Individuals who are HIV negative also provide information on risk behaviours and the determinants of behavioural change.

The study has evolved as knowledge about HIV and AIDS has progressed. For example, the variables which are measured are reviewed, adding or subtracting variables based on the literature and their suspected explanatory power. Examples of revisions to the VLAS include collection of social determinants such as socio-economic status and social support and collection of nutritional information. The methods of data collection have also changed over time to accommodate advances in testing (e.g., viral load). Most recently, the research in HIV/AIDS has focused on genetic aspects of the disease. The VLAS now collects measures from subjects on genetic markers which may be important in understanding prevention and progression of the disease.

The analysis and reporting of VLAS findings is conducted by HIV/AIDS research partners across Canada. As well, Canada participates in the Tri-Continental Seroconverter Study (with Holland, Australia and the United States). Together, these researchers exchange and collaborate on study results and design. The VLAS project directors also collaborate with HIV/AIDS researchers in Quebec who are implementing a cohort study of young gay men (the Omega study).

(b) Effectiveness and Lessons Learned

The VLAS has generated over one hundred publications including refereed papers and letters.[3] The VLAS findings have had important impacts on researchers' understanding of the incidence and risk factors associated with the disease and the clinical progression and natural history of the disease. The study has also informed public policy. Examples of impacts and effects include:

- ☐ Contribution to the identification of risk factors related to HIV/AIDS, such as sexual practices, number of partners and other socio-demographic determinants such as education and use of alcohol/ substance abuse. This research has had important policy implications in terms of the prevention messages which must be conveyed to at-risk groups.
- ☐ The VLAS also tracks those practices or characteristics which seem to delay or inhibit the progression of the disease.
- ☐ Use of the data to do "back calculation". In the early stages of the epidemic there were no direct methods available to calculate the prevalence of HIV. Modelling techniques based on incidence rates in the VLAS data permitted an estimate of the prevalence of HIV which is a critical to policy planning and for resource utilization.
- ☐ The detailed understanding of the progression of the disease contributed to the development of a system of "staging" of the disease which allows practitioners and researchers to talk about the disease in a consistent way.
- ☐ Tracking of the effect of new treatments. The introduction and effectiveness of AZT, for example, is visible in the VLAS data marked by a deflection in the disease progression curve.

The key difficulty encountered in the implementation of the VLAS has been around continued funding. The NHRDP grant is based on a three-year cycle. The VLAS has had to apply for funding from the organization regularly, about four or five times over the life of the study. This has led to continued uncertainty about the viability of the project. The most recent grant for the study terminates in October 1997 and the NHRDP has sent signals that funding for cohort studies which tend to be lengthy and expensive will no longer be provided by the program.

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[3] Examples of recent publications are provided at the end of this report.

Other difficulties are related to the challenge of conducting a cohort study in a rapidly changing research field. Problems related to attrition are endemic to cohort studies and it has been challenging at times to maintain follow-up and participation over the lengthy period time. Comparative data analysis has also indicated that the VLAS is subject to biases such as volunteer and survivor bias which decreases the representativeness of the study sample.

Issues around confidentiality and the validity of the responses (i.e., given the personal nature of much of the information) have also arisen during the course of the study. In response, the VLAS has developed a sophisticated "triple-coding" system to reassure participants of their anonymity and to encourage candid responses.

Finally, the rapidity of discovery in the field of HIV/AIDS research can pose significant challenges for planning research. Continual changes to diagnostic tests and the anticipation of the key determinants is crucial to the usefulness of the data. Success is predicated on being able to be at the "cutting edge" of research in the field.

(c) Examples of Publications

Examples of publications which have resulted from the VLAS include:

Craib, D. et. al. "Concise communication: Post-serconversion serum HIV-1 RNA: A predictor of long-term mortality in HIV infection", *Journal of Acquired Immune Deficiency Syndromes*, in press.

Hogg, R. et al. "Analysis of nutritional intake in a cohort of homosexual men", *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 9:162-167, 1995.

Hogg, R. et. al. "Lower socioeconomic status and shorter survival following HIV infection", *The Lancet*, 344:1120-24, 1994.

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Schechter, M. et al. "Progression to AIDS and predictors of AIDS in seroprevalent and seroincident cohorts homosexual men", *AIDS*, 3:347-53, 1995.

Schechter, M. et.al. "Use of the markov model to estimate the waiting times in a modified WHO staging system for HIV infection", *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 8:474-79, 1995.

Strathdee, S. et al. "Lack of consistency between five definitions of nonprogression in cohorts of HIV-infected serconverters", *AIDS*, 10:959-965, 1996.

4. Vaccine Development Research Program

(a) Project Description

The Vaccine Development Research Program became part of the National AIDS Strategy — Phase II (NAS-II) in September 1994. NAS-II is currently the sole funder of this research. The mandate of the research, to develop an HIV/AIDS vaccine, is directly in line with NAS-II priorities to evaluate the possibility of developing an HIV/AIDS vaccine. The philosophy upon which this research is based is that, given that most individuals now being diagnosed with HIV cannot afford antiviral therapy or would not be able to reliably follow this rigorous approach to controlling AIDS, it is important that an AIDS vaccine be found as quickly as possible. The importance of developing a vaccine is heightened with the realization that an estimated 8,000 new HIV infections occur every day world wide. While the primary clients of this work are seen to be the global vaccine development community, ultimately every living person will benefit.

The research being undertaken uses the SIV/Macaque model to evaluate the effectiveness of the attenuated vaccine approach to HIV/AIDS vaccine development. The simian immunodeficiency virus (SIV) is a virus that infects monkeys and causes AIDS. Genetically SIV is related to HIV-2 which [illegible] a virus leading to AIDS in humans, although not to the same extent as HIV-1. The SIV/Macaque model is considered to be a perfect model for HIV as the monkeys develop similar symptoms to humans, for example: CD4 drops and virus load can be used to test progression to AIDS. Neurological symptoms are also similar as are the diseases and gastro-intestinal problems. Basically, SIV in monkeys simulates as closely as possible HIV in humans. It also takes less time for monkeys to develop AIDS (i.e., one to three years) than it does humans (mean of 10 years). The Vaccine Development Research Program has evaluated the extent to which this approach protects against heterologous (i.e., breadth) challenge.

The first step in the process is to vaccinate the monkeys with the attenuated vaccine. This vaccine will infect the monkeys, but it will not cause disease. After a period of time (e.g., three months, six months, a year and a half), the monkeys are challenged with a virus to see if a second virus can be prevented from infecting the monkeys and causing disease. The best result would be sterilizing immunity which means the second virus does not infect. However, a transient infection in which a low level infection occurs and disappears within a couple of weeks would be a more likely outcome.

The attenuated vaccine approach is considered to be the only promising approach to HIV/AIDS vaccine development. This belief has been expressed by the Noble Laureate David Baltimore and by the World Health Organization (WHO) which has also come to the conclusion that this is the best approach.

This approach to vaccine development is unique in that no commercial organization has taken on this approach to HIV/AIDS vaccine development as it has some risks associated with it. While attenuated virus vaccines have the advantage over other vaccines in that they behave like the natural infection in terms of the immune responses they induce, they also have the disadvantage in that there is the potential that the virus will revert to a more virulent form. In terms of HIV/AIDS, this means a life long disease and death. In order for companies to take such a risk, there would have to be a guarantee that the company would be protected from law suits and that the health care system would ensure treatment of infected individuals.

The only frustration experienced regarding the research has been with regard to the cuts to its budget and the potential closure of the Macaque colony. The closure of this colony would be detrimental to the vaccine research as it is the only colony that is a non-commercial source. The colony is well maintained and the monkeys are kept in pristine condition (i.e., when the monkeys are used for research, there is no question as to their health).

Collaborations have been undertaken with a number of academic, commercial and government organizations in Canada, the United States and Europe. Examples of these partnerships include: McGill University, IRCM, University of Ottawa, NIBSC in the United Kingdom, Karolinska Institute in Sweden, Paul Ehrlich Institute in Germany, NIH in the United States and Chiron Corp in the United States. These collaborations have helped to unify their understanding of the effectiveness of this approach to HIV/AIDS vaccine.

(b) Effectiveness and Lessons Learned

The primary impact of the Vaccine Development Research Program activities has been to prove to the vaccine development agencies throughout the world that this approach is very promising if not a little risky. As already mentioned, the value of this approach has been noted by Noble Laureate David Baltimore from NIH and WHO. The research has also been presented at several scientific conferences, both nationally and internationally, over the past two years and the researchers have been nominated for awards in both Canada and Europe for their work in this area.

The results of this vaccine research have been disseminated in a variety of ways. First, the results have been presented at several national and international conferences which they have attended over the past two years. Several students and post-doctoral fellows (e.g., from McGill university, from Germany) have also been involved in this project. Finally, the researchers have written and co-authored several papers over the past two years.

The safety aspect of this approach is the only limitation to starting the process of vaccinating people with an attenuated vaccine. As already noted, one of the disadvantages of an attenuated virus vaccine is that it can revert and infect the vaccinee. Consequently, this safety aspect needs to be explored further using the model that has been developed at Health Canada as part of NAS-II.

It is crucial that a vaccine to stop the spread of AIDS world wide is found. The strength of this program in achieving that goal is the academically sound vaccine evaluation group. The limitations are considered to be money and a strong political and financial commitment from the Government of Canada.

The main challenges currently facing the vaccine development research is trying to get this type of vaccine into general use without more safety evaluations. As safety evaluations are long term, needing three to five years, a real commitment is required from the program's funding agencies and the medical community.

(c) Examples of Publications

Examples of publications which have resulted from this research and as part of the collaborations undertaken include:

Almond, N., Kent, K., Cranage, M., Rud, E., Clarke, B. and Scott, E.J. "Protection by attenuated simian immunodeficiency virus in macaques against challenge with virus-infected cells", *The Lancet*, Saturday, May 27, 1995, Vol. 345, No. 8961.

Kent, K. and Rud, E. "Progress with HIV vaccines" in *The Molecular Biology of HIV/AIDS* edited by A.M.L. Lever, 1996.

Letvin, N.L., Li, J., Halloran, M., Cranage, M.P., Rud, E. and Sodroski, J. "Prior infection with a nonpathogenic chimeric simian-human immunodeficiency virus does not efficiently protect macaques against challenge with simian immunodeficiency virus", *Journal of Virology,* July 1995.

Putkonen, P., Nilsson, C., Makitalo, B., Biberfeld, G., Thorstensson, R., Cranage M. and Rud, E. "Immunization with live attenuated SIVmac can protect macaques against mucosal infection with SIVsm", *Vaccines 96,* 1996.

Rud, E., Cranage, M., Yon, J., Quirk, J., Ogilvie, L., Cook, N., Webster, S., Dennis, M. and Clarke, B. "Molecular and biological characterization of simian immunodeficiency virus macaque strain 32H proviral clones containing *nef* size variants", *Journal of General Virology,* Vol. 75, 1994.

Scott, E.J., Almond, N., West, W., Kent, K., Cranage, M.P. and Rud, E. "Protection against simian immunodeficiency virus infection of macaques by cellular or viral antigens", Neuvième Colloque des Cent Gardes, 1994.

Whatmore, A., Cook, N., Hall, G., Sharpe, S., Rud, E., and Cranage, M.P. "Repair and evolution of *nef* in vivo modulates simian immunodeficiency virus virulence", *Journal of Virology,* August 1995.

5. Street Connections

(a) Project Description

Street Connections is the amalgamation of two pre-existing street outreach programs which were being administered by Mount Carmel Clinic in Winnipeg, Manitoba: P.O.W.E.R. — a pre-existing community support group for prostitutes; and Street Station — an HIV prevention program targeting street-involved individuals. Due to the similarity of program activities and philosophies, the overlap of target populations and the ending of project funding for P.O.W.E.R., the Clinic submitted a proposal to Manitoba Health to amalgamate the two programs. Street Connections was initiated in April 1995 with funding from Manitoba Health. The mission of the program is to facilitate and support healthy change and growth within street-involved individuals which will move these individuals towards independence and integration into a healthy community. Its objectives include:

- ☐ to improve clients' abilities to advocate on their own behalf to meet their basic needs;
- ☐ to reduce the risk and consequences of HIV, STDs and other communicable disease transmission;
- ☐ to reduce the risks associated with substance abuse;
- ☐ to reduce the risks and consequences of violent assault;
- ☐ to promote healthy families by encouraging reproductive planning, healthy pregnancies and positive parenting; and
- ☐ to improve client access to integrated services, resources and training.

While Street Connections has not changed its objectives formally since it was initiated in 1995, informally they are beginning to work with communities to ensure used needles are disposed of appropriately. In addition to disposing of used needles themselves if they are able (i.e., have the resources), they have produced a brochure that explains how to properly dispose of used needles and distribute "sharps" containers to local agencies.

The primary philosophy behind Street Connections is "harm reduction". As such it provides a variety of health, social and bridging services to street-involved individuals in a non-judgemental manner. They also play an advocacy role through bringing harm reduction into mainstream agencies, such as Family Centres. By having members of these agencies working in their offices, they are able to help mainstream organizations understand what Street Connections does and give them a different point of view regarding street-involved individuals. Street Connections operates out of two sites (a house which is open to females, their children and transgender clients and a storefront location) and a mobile van which travels throughout various inner-city neighbourhoods stopping at specific street corners as well as making home visits upon request. The main activities of Street Connections include:

- ☐ ***drop-in/resource centres***: Both sites have scheduled hours within which clients can drop in. In addition to helping clients meet their basic needs, such as warmth/nourishment and access to a washroom, there are also recreational activities available (e.g., games), a weekly dinner, a telephone and someone to talk to. They also have formal planned activities (e.g., AIDS Bingo, guest speakers).
- ☐ ***outreach***: While outreach mainly occurs through the scheduled evening van stops and home visits, staff also have contact with clients, for example, in court, while they are incarcerated and at other agencies. Outreach is also achieved through the weekly distribution of *Street News* which provides up-to-date information on program activities and services, as well as short pieces on issues such as safety, health and parenting.
- ☐ ***needle exchange***: Used needles are exchanged for new needles. If a client does not have a used needle to exchange, they are given a maximum of two new needles and informed or reminded that the program operates as an exchange. Currently, up to 500 bundled needles will be exchanged at one time as a way of encouraging exchanges at "shooting galleries"[4].
- ☐ ***health services***: While all program staff can provide health information and counselling, there are two nurses located at the sites to aid clients in accessing a wide range of health services, such as access to health supplies (e.g., condoms, lubricants, latex gloves, "vein" cream), expanded nursing assessment and treatment, and referrals to doctors and health agencies. They also offer information and care on reproductive health issues, such as birth control, prenatal issues, infectious diseases including STDs, HIV/AIDS, hepatitis, tuberculosis and life style health problems including mental health.
- ☐ ***contract services***: Access to available resources in the community is provided with some services being provided on-site. For example, Klinic Community Health Centre provides a counsellor and the Family Centre of Winnipeg provides a family education worker on-site. For other services, access is provided through referral.
- ☐ ***client case management***: Clients accessing the services of the program on an ongoing basis have a file opened (at the client's consent) and a staff case manager assigned to them. The case manager conducts a needs

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[4] A house or apartment where large numbers of people go to purchase and use drugs.

assessment and then either delivers or coordinates services provided by other staff or other agencies.

- ☐ *counselling*: Counselling is provided by all direct service staff on issues ranging from health and safety to education and training. While crisis intervention counselling occurs regularly, counselling sessions may also be scheduled.

The primary funder of the program is Manitoba Health, with funding from contract staff generally provided through the contract agencies budgets. Street Connections does occasionally receive funding from individual donors. NAS-II does not fund this program.

Street Connections' target population is street-involved individuals and families within Winnipeg's inner city. More specifically, this includes male and female prostitutes, street youth, solvent users and intravenous drug users. In 1996/97, 64 per cent of the program's contacts[5] were female and 74 per cent were aboriginal. In terms of more in-depth encounters[6], between April 1996 and January 1997, 84 per cent of encounters were with females and 69 per cent were aboriginal. While contact information is maintained, it should be noted that it is not completely accurate. For example, when needles are exchanged for a "shooting gallery", there is no way of knowing exactly who will be using them.

Street Connections is innovative for a number of reasons. First, there are very few programs that provide integrated service delivery, including access to mainstream resources, in their area. Second, there is no other formally funded needle exchange program in the province of Manitoba. Third, it provides very easy and quick access to nursing care at both sites, as well as occasionally in the van. Clients are able to walk-in off the street and get the nursing assistance (e.g., test for HIV) they need.

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5. Contacts refers to all in-person or telephone contacts made and does not refer to specific individuals (e.g., 10 telephone calls would be counted as 10 contacts regardless if three of them were made by the same person).

6. Encounters refers to occasions where clients have more in-depth, individually documented interaction with staff.

Also, given the non-judgemental manner in which clients are treated by staff (e.g., nurses will teach clients ways to reduce the incidence of cellulitis and infections while "shooting-up"), clients will be very open and honest about what the problem is and the circumstances surrounding it.

There have been a few barriers to carrying out the activities of Street Connections. One barrier is the more conservative climate in which they operate. Consequently, people are not as open to the existence of programs such as the needle exchange. Another barrier noted was the justice system. Police are seen as adopting a more American approach to arresting people using drugs. This becomes problematic in that the police see Street Connections as working at cross purposes. A final barrier noted concerns the attempts of businesses and residents of the inner city to clean up their neighbourhood. It is the perception of some businesses and local residents that Street Connections is enabling the activities and behaviours of the very individuals (people living on the street) they are trying to move out of their neighbourhoods.

Street Connections has developed both formal and informal partnerships with a number of other agencies and community groups which focus on issues affecting people living on the street. More specifically, partnerships have been developed with groups focusing on, for example, juvenile prostitution, outreach to gay clients, solvent abuse, HIV prevention, services for HIV+ individuals, addiction treatment for pregnant women, food banks, development of aboriginal services, downtown safety and inner city community concerns. The most formal partnerships in which roles are defined are those with the contract agencies who either have staff working at Street Connections' sites or accept referrals from Street Connections. Of note is that by using its connections to other agencies, staff at Street Connections can facilitate clients receiving the assistance they need (e.g., housing, child care) by connecting them to the appropriate services. Other agencies with whom they would like to develop partnerships with in the future include Legal Aid, Addictions Foundation of Manitoba and aboriginal service agencies.

These partnerships are perceived to have been very effective in helping Street Connections reach its objectives. There is also good coordination and collaboration between the partners to ensure that the various agencies are not working at cross purposes or duplicating services. For example, on nights when Village Clinic (a program geared towards gay men) is doing their outreach, the Street Connections van coordinates with them to ensure they do not stop on the same streets as Village Clinic staff. They also coordinate with referral sources, such as Manitoba Mental Health, to ensure that the services the client is receiving are as streamlined as possible. Generally speaking, every effort is made to supplement or complement the services of other agencies, rather than duplicate them.

(b) Effectiveness and Lessons Learned

The activities of Street Connections have had a number of positive impacts. In 1996/97, a total of 25,856 contacts were made with their target population, averaging 2,155 a month. During this same year, there were a total of 2,003 in-depth encounters. It is the feeling of respondents that through the counselling support they provide their clients or access to other programs, Street Connections has had a positive impact on many of their clients. This is particularly true in terms of those clients with whom they are able to facilitate some planning because they work with them on a long term basis. Counselling provided around reproductive health is also seen as having been very beneficial. Staff help the individual prepare for birth, help them access treatment or decrease their substance abuse during pregnancy, help them to stabilize their housing and provide them with parenting support. Finally, the needle exchange program has had positive impacts. Between September 1994 and August 1995, 958 drug users were registered with the exchange program. In 1996/97, 262,058 new needles were given out and 259,780 used needles were exchanged. This makes the rate of needle exchange to be greater than 99 per cent. Anecdotally, staff of Street Connections have been informed that the existence of the needle exchange program has resulted in fewer used needles being disposed of improperly.

There have also been a couple of unintended impacts. It is the perception of some business owners that the activities of Street Connections have indirectly caused them to lose some business due to the presence of their clientele in the area. On a more positive note, through a section in *Street News* that provides information regarding "bad date" experiences of prostitutes, one staff member noted a recurring description. This staff member undertook some research in collaboration with the police which resulted in that individual's arrest.

In terms of HIV/AIDS, the main focus of Street Connections is education and prevention primarily through the needle exchange program. A lot of energy is put into this program and attempts are made to keep up-to-date, particularly regarding the dynamics of the "shooting galleries". They also have promotional material, such as posters and pamphlets, and they conduct an AIDS Bingo. AIDS Bingo entails throwing out an AIDS related question after every number is called. This activity indicates that people are really well educated on the issue. Finally, they do presentations and in-services. For example, they go into youth centres and conduct small group talks around street issues. The purpose is to try and catch youth who are on the border line and provide them with information. Other places where presentations are conducted include schools and other agencies.

Information about this program has been disseminated widely both within the province of Manitoba and outside. Recently two staff members were at a conference on needle exchange programs in San Diego. At this conference, they spoke on integrated service delivery at a plenary session. Although other organizations have requested information about their program, the extent to which the program is adopted is not known as there is no follow-up. It is known, however, that one organization has recently adopted their approach. As it is generally believed that the focus on harm reduction can be transferred to any population or setting, the activities of Street Connections are seen as providing a starting point for other organizations to adapt to their environment.

Given the target population of Street Connections (i.e., street-involved individuals), the extent to which their activities can be adapted to reflect changes in the epidemic are limited. However, recent changes in the epidemic indicating a higher proportion of intravenous drug users, as well as changes in drug use, has prompted Street Connections to refocus on the needle exchange program. Given their broad mandate, the needle exchange program has perhaps lost some of its focus.

This program has a number of strengths. First, they have built up trust with their clients which has resulted in clients accepting their help. Second, they are able to connect on an ongoing basis with people who are marginalized in a positive and strong way. Third, they are able to help clients access a variety of other services. Fourth, given the wide range of backgrounds of their staff, they are very adaptable. Fifth, they have stable funding. In terms of weaknesses, only two were noted. First, to this point they have been unable to get the community involved and solicit their support and second, they have not raised awareness of the program.

There are two main lessons learned as a result of this program's activities. First the community and police should have been brought into the program from day one. Based on the operating philosophy of one of the originating programs, the activities of Street Connections have been kept pretty much to themselves. The belief now is that there is value in being seen in the public and the community in terms of having community support. A second lesson learned is that it takes a lot of time and energy to keep two sites running. While this is perceived as a challenge, it is also seen as a value because activities are different.

Changes to how services are delivered are constantly reviewed. One of the challenges that they face is that they have very limited resources to allocate over a broad based mandate. The question becomes, where do you focus your energies? This is one of the downsides of being an integrated service delivery — you tend to be spread relatively thinly.

6. Fourth Canadian Aboriginal Conference on HIV/AIDS and Related Issues

(a) Project Description

The Fourth Canadian Aboriginal Conference on HIV/AIDS and Related Issues was held from November 9 to 13, 1996, in Halifax, Nova Scotia. The conference was hosted by Atlantic First Nations AIDS Task Force headquartered in Halifax. The Atlantic First Nations AIDS Task Force's Board is comprised of practically every Band, Tribal Council, and Aboriginal Organization in the Atlantic region.

Planning for the Conference began immediately after receiving delegate support at the Third Aboriginal Conference on HIV/AIDS (held December, 1994, in Toronto). A letter of intent was prepared and submitted to the Medical Services Branch at Health Canada. This was followed by the solicitation of letters and resolutions by approaching Chiefs and other Aboriginal organizations, first regionally, then nationally. The objective of this stage was to secure support for the conference itself.

A Local Conference Management Committee was established in order to oversee the conference planning activities. Before a full proposal was prepared, two national consultations were held with various Aboriginal stakeholder organizations. The first was held with over 30 representatives from various Aboriginal and government stakeholders in Toronto on March 8, 1996. The second, held in Ottawa later on March 27, 1996, was to allow those organizations who could not attend the first consultation to provide their input. Approximately 15 participants attended this session.

Support was received from a majority of these national organizations and many letters of support were received from across Canada. A full proposal was submitted and approved about eight months before the conference was scheduled.

The theme of this conference was "Healing Our Nations". This theme was "chosen to reflect the tremendous healing power found in the cultural and traditional ways of Aboriginal People." It also represents the work and efforts being made by the Aboriginal community regarding HIV/AIDS.

The overall goal of the conference was to give Aboriginal people living with HIV/AIDS an opportunity to voice their needs, concerns and experiences. To support this goal, a series of 17 objectives were identified. They were:

- ☐ to bring together Aboriginal people living with HIV/AIDS, Aboriginal communities, the scientific, research and medical establishment and community and government agencies;
- ☐ to ensure that the voices of Aboriginal youth and persons living with HIV/AIDS be heard by placing emphasis on their ideas and inclusion throughout the process from the planning stage to the implementation stage of the conference;
- ☐ to provide information and empowerment techniques to Aboriginal people living with HIV/AIDS to help manage their condition through a skills building approach;
- ☐ to provide an opportunity for the identification of additional programs/services needed to reduce the risk of transmission of HIV, HBV and other bloodborne infections including the injection-drug-using community;
- ☐ to examine the needs and gaps around HIV surveillance and research issues among the Aboriginal populations;
- ☐ to recognize and reflect the cultural and traditional strengths and diversity of Aboriginal communities;
- ☐ to provide skill-building opportunities that will help design and deliver programs to meet the needs of Aboriginal people living with HIV/AIDS and youth in regards to education and training programs;

- ☐ to offer an environment that encourages dialogue and to strategize an effective response to the needs of Aboriginal people living with HIV/AIDS and Aboriginal youth within a holistic framework;
- ☐ to increase Aboriginal ownership in addressing the many related issues underlying HIV/AIDS in a way that stresses a holistic approach;
- ☐ to provide delivery of the latest treatment/research issues and information;
- ☐ to share information and provide opportunity for establishment of partnerships with correctional institutions/facilities to determine the type of educational programs required to meet the needs of their HIV/AIDS Aboriginal inmate/parolee populations;
- ☐ to share critical information that will help design and deliver HIV/AIDS prevention education for integration into existing health care and after care programs administered by Corrections Services Canada;
- ☐ to identify and make recommendations regarding the issues surrounding: Health Transfer process, MSB Devolution, Non-Insured Health Benefits Management and Inter-jurisdictional debates, especially as they impact HIV programming and services;
- ☐ to develop and design a process for the creation of a stronger voice nationally which will provide support to regions which have historically been excluded in terms of national funding support by including NWT and the Eastern Delegations;
- ☐ to provide a forum for delegates who attend the conference to share with one another other related issues not addressed in the conference agenda;
- ☐ to discuss and exchange information and network on Aboriginal HIV/AIDS and related issues; and
- ☐ to provide an opportunity for the AIDS organizations to network among various professions that serve Aboriginal communities.

At final count, there were 360 registered delegates. Almost half of these (132) received full or partial sponsorship to attend. The conference lasted three days and included 35 workshops centred around the following five "streams": research and surveillance (6 workshops); psycho-social issues (11 workshops); education, prevention and outreach (10 workshops); community/organizational development (6 workshops);

and treatment information (2 workshops). In addition to opening and closing addresses, there was a panel of five Native individuals living with HIV/AIDS who spoke to the conference attenders about their lives.

It is only the second time that a community-based organization planned and hosted a national Aboriginal AIDS conference. The first two conferences were held in Vancouver and were closely affiliated with academia. As well, at this conference, more than one half of the presenters were Aboriginal and therefore was a better reflection of the increase in expertise being developed in Aboriginal communities. While some regions hold their own conferences (e.g., British Columbia), this is the only national AIDS conference held that is geared toward Aboriginal populations. Furthermore, this conference was considered to complement regional conferences (in fact, the organizers shared some of the lessons learned with the B.C. Aboriginal AIDS Conference organizers).

The primary funding partners for this project included Health Canada (via the National AIDS Strategy), Correctional Service Canada, Indian and Northern Affairs Canada, Canadian Heritage and the Atlantic Health Advisory Board. In addition, the following also provided funding or in-kind support: GlaxoWellcome, Merck Frosst, Kevin Barlow (First Nations Health Consultant), Halifax Regional Municipality, Union of Nova Scotia Indians, Union of New Brunswick Indians, Micmac Native Friendship Centre, Province of Newfoundland and Labrador, various regional and national Aboriginal organizations (in-kind support and advice) and a number of university faculties (volunteers).

Not only was Health Canada involved in a funding capacity, but it is believed that without their support, the organizers would have been unable to leverage funds from other sources. In addition, the assistance of the MSB in securing funds was mentioned specifically as providing a great deal of assistance.

Overall, the conference was considered to be a success. One of the major impacts of the conference was to provide hope to those living with HIV/AIDS that something is being done. As well, a great deal of information was imparted at the conference. The testimonial component of the conference (by PHAs) contributed to the emotional impacts. To support these impacts, the ceremonial people present played a major role. Another impact was that the conference served as a model of Aboriginal ownership at a national level. Other impacts mentioned were political and controversial. This in reference to the media attention as a result of the criticisms made by the conference coordinator regarding the absence of the federal Minister of Health and National Chief Ovide Mercredi at the conference.

A number of resolutions were also passed at the end of the conference. One of these resolutions pertained specifically to the National AIDS Strategy:

> "Resolution: That there be a consistent effort to maintain a National AIDS Strategy towards addressing HIV/AIDS which affects all Aboriginal across our lands within this place we live as human beings. Aboriginal women's issues relating to HIV/AIDS be more strongly advocated and implemented within the Strategy of National HIV/AIDS Federal Initiative. Inter-jurisdictional issues and barriers be acknowledged in a more co-operative manner when addressing services on/off-reserve, especially urban centres."

(b) Effectiveness and Lessons Learned

One of the primary challenges was securing the funding for the conference. In order to "sell it" to Health Canada, they had to solicit a number of letters of support and hold the consultations to show that there was support and therefore a need for the conference. Another challenge was trying to make the delegate representation fair across geographic location and cultural diversity. When numbers for one area or cultural group were low, the organizers had to defend the result (e.g., only two delegates applied from that area or group).

The strengths of the conference were the use of ceremony and song to bring the different cultural groups and bands together (representatives from over 50 tribes were present) as they serve as the common bond between them. The role of elders and ceremonial people was very strong and was considered to have been key to the success of the conference. As well, the report was praised for its comprehensiveness and overall quality.

One of the main weaknesses identified was that there were no resources allocated to wrap-up the loose ends after the conference and to write the report. As well, the organizers could have used another three or four volunteers overall. One of the presenters commented that a "hotel conference" is not culturally appropriate for an Aboriginal conference. Instead, it was suggested that a gathering such as this could have been held at houses of learning on reserve, at a technical college with cultural understanding, or at a sweat lodge.

Some of the lessons learned include:

- ☐ would not have held the conference on a long weekend;
- ☐ they anticipated too many people (just over half of the expected number registered);
- ☐ because the conference was held in the Atlantic region, there were not many attenders from British Columbia or Alberta; and
- ☐ because of the emotional atmosphere at the conference, the media and government representatives should not have been allowed to attend the closing ceremonies.

7. Healthy Choices Project

(a) Project Description

The Healthy Choices project is run by ACCESS, The AIDS Committee of Sudbury (Le comité du sida de Sudbury), a bilingual community-based organization. While the Healthy Choices project does not have a mission statement of its own, it fits very well into that of ACCESS: Promoting wellness and supports to individuals and the whole community in a healing response to HIV/AIDS. The Healthy Choices project has three main sub-projects:

1) Man to Man: to prevent further spread of HIV among men who have sex with men;
2) Positive Living: to develop health promotion activities for PHAs living in the Sudbury and Manitoulin District; and
3) Service Providers in the Community: to create a supportive social environment within the Sudbury and Manitoulin District for PHAs, for people at risk of HIV infection, caregivers, families and friends.

The activities of the Man to Man project include a number of workshops on various topics (identified by the target group) including safer sex issues. As well, there are a number of public forums on safer sex and HIV organized for men who have sex with men as well as presentations on self-esteem (addressing issues such as internalized homophobia). In particular, staff visit the local gay bar on a monthly basis to distribute written information and condoms and the organization provides HIV/AIDS information kits for frosh (new student) packages (distributed each August). Also, there is ongoing coordination of the Gay and Bisexual Men's Support and Discussion and the LesBiGay Youth Groups. Lastly, there is a poster and pamphlet campaign to be distributed during AIDS Awareness Week.

The Positive Living project includes the presentation of three workshops per year (topics are determined in consultation with the target group) as well as other health promotion activities including coordination of social activities (monthly), ongoing dissemination of treatment information and updates, and the continuous recruiting and training of volunteers to act as peer leaders. The theme for the last year (and presented in the 1997-1998 workplan) is "Looking after ourselves means more than using condoms".

The plans for the Service Providers in the Community component includes the development of a train the trainer program on Homophobia and HIV (bilingual), and the subsequent training of six agency volunteers to deliver homophobia and HIV education.

The history of ACCESS begins with its incorporation in 1989. As a result of the homophobic environment in the Sudbury region, a need for education and support was identified and the AIDS Committee of Sudbury was begun. Originally, two part-time outreach positions were created: one targeted toward aboriginal populations; the other toward homosexual men. Activities of the latter included safer sex workshops and presentations on homophobia.

When Phase I of NAS began, the position geared toward homosexual men became a full-time paid position (funded by NAS-I). The activities undertaken were geared mostly toward the policies and procedures in institutions regarding HIV/AIDS (e.g., hospitals, incarceration institutions).

When NAS-II began in 1993, the staff position changed again and became a bilingual position. It was at this time also that the Healthy Choices project began. The Healthy Choices project was designed keeping in mind a number of the lessons learned from the first phase: the project must be more focused; a bilingual coordinator was required to reflect the bilingual composition of the community; and due to provincial funding priorities, the federally-funded project would not provide counselling services.

The Healthy Choices project is considered to be innovative due to the targeted nature of the services (gay and bisexual men, people living with HIV/AIDS, and the community as a whole in terms of attitudes toward homosexuality). As well, activities are centred around prevention and education activities. Moreover, this is the only organization currently offering these services in the community. The project is also innovative from the standpoint that the project coordinator is a bilingual position. Finally, the team approach is considered to be innovative and a key to success.

The project is 100 per cent funded by NAS-II. Other partners that have been developed include other ACAP-funded organizations (information sharing, networking), the Ontario AIDS Network, and various organizations in the community (e.g., HIV Medical Clinic, Health Unit, hospitals, schools (all levels)). Many of these partners were existing from Phase I of NAS, but Phase II encouraged more partners including a number of francophone groups such as the francophone Health Unit and the francophone college.

(b) Effectiveness and Lessons Learned

Several challenges encountered at the time the Healthy Choices project was starting up were mentioned, including:

- ☐ the service user profile was evolving as the bar scene was in transition at the time the project was starting;
- ☐ the target group was particularly hard to reach as some did not want to be helped and many did not want to be identified as homosexual and/or HIV positive;
- ☐ the gay community in the Sudbury area was said to be unable to organize itself;

- ☐ at the time of project start-up, the newly-hired bilingual coordinator was new to the area and found the unfamiliarity with the region, city, and target population particularly challenging (e.g., identifying and "winning over" the gatekeepers to the gay/bisexual community);
- ☐ less than a year after project start-up, another local community-based organization targeting to homosexual men collapsed resulting in a gap in service delivery to this population group; unfortunately, much of that organization's activities fell beyond the scope of the Healthy Choices project; and
- ☐ documentation was also considered to be a challenge, as the target group does not want to be identified in literature and reference materials.

Ongoing challenges include the cyclical nature of the participation of individuals living with HIV/AIDS in the various programs. As well, the fact that funding is secured on a contract basis makes it very difficult for organizers to do long term planning. Finally, bisexual men were mentioned as being particularly hard to reach.

Some of the strengths of the project include the team approach by ACCESS staff. As well, the staff is very stable (low turnover) which reinforces the relationships the staff develop with clients, thereby enhancing service delivery. Another positive aspect of the project is that it is working: information is being disseminated and participation in activities has increased every year. It was also mentioned that resources available through NAS are very good and that they do not need to "reinvent the wheel". Other strengths mentioned included targeting individuals living in urban areas with a "rural mentality" (in terms of homophobia, "coming out", for example), and the maintenance of a web page.

The weaknesses include the localized nature of service delivery and consumption (although this is becoming less of a problem as the surrounding communities are slowly becoming more involved in these issues). Another weakness is the dilemma being faced with regard to acquiring bilingual resources. Although free resources are readily available from Toronto, they are only available in English. The result is that they must then be translated (for which there is no budget) and then the bilingual resource must be photocopied. Historically, the Clearinghouse could provide bilingual resources that were considered to be very good, but now that the Clearinghouse charges user fees, this is no longer a feasible source for resources (again, there is no budget for procuring resources).

Some suggestions for improvement would include: a travelling budget which would allow outreach to smaller communities; and an outreach budget that includes not only photocopying, but advertising and resource procurement also.

Lessons learned include (lessons taken from the Critical Work report[7] are marked with an asterisk):

- coordination of the Healthy Choices project cannot be a part-time effort;
- evening information lines and "safer sex parties" do not work in this community;
- in general, people are very interested and want to work with the lesbigay community — they need the door to be opened;
- if there is no place where you can meet community members, create one*;
- ask your community what it needs or wants*;
- create an atmosphere of openness*;
- establish ground rules similar to the motto of Healthy Choices' men's discussion group: What you say here, what you hear here and who you see here, stays here*;
- respond to needs expressed by participants, follow through by making the changes indicated by evaluations*; and
- use existing resources and documents wherever possible.*

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[7] AIDS Committee of Sudbury. Critical Work: Sustaining Men Who Have Sex with Men Programs in Canada.

As well, a number of recommendations were made pertaining specifically to evaluations:

- ☐ develop alternative ways for participants to complete evaluations, including returning them by mail, fax or the Internet (although the last two methods could not guarantee privacy)*;
- ☐ talk with participants to determine their concerns about the evaluation, what alternatives do they suggest?*;
- ☐ test questions with focus groups to ensure they are clear and understandable*; and
- ☐ talk to respondents after the data are collected to determine how they felt about the evaluation process*.

Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT 12:
Expert Panel Review

September 2, 1997

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Evaluation of the National AIDS Strategy, Phase II

TECHNICAL REPORT No. 12: Expert Panel Review

Expert Panel Members

A pool of potential panel members was formed through nominations from the Evaluation Advisory Committee, program staff, external expert advisors and the consultants. Selection criteria were specified, allowing for representation on the panel of expertise in the following areas: prevention and education; care, treatment and support; research; aboriginal populations; ethnocultural populations; and prison populations. The Evaluation Advisory Committee also stipulated that at least one expert should be from UNAIDS or another external organization, and at least one should be an international-calibre researcher. From an initial list of thirty-four nominees, a selection was made by the consultants of 20 individuals, representing at least one first choice and one alternate in each of the above six categories. The first choices were then contacted, and if they declined, the alternate was invited to participate. Within one of the categories, three individuals declined to participate, leaving no available alternates. The final panel was therefore composed of nine members, eight of whom provided responses. They were:

Dr. Liviana Calzavara
HIV Social, Behavioural and Epidemiological Studies Unit
University of Toronto

Area of expertise: Epidemiology, Special populations

Dr. Don Des Jarlais
Chemical Dependency Institute
Beth Israel Hospital
New York, New York

Area of expertise: HIV/AIDS and injection drug users

Dr. Iain Mackie
Vancouver General Hospital
Vancouver, British Columbia

Area of expertise: Care and treatment

Dr. Anita Rachlis
Division of Infectious Diseases
Sunnybrooke Hospital Centre, Toronto

Area of expertise: Care and treatment; clinical research

Mr. Marcel J. Dubois
Montréal, Québec

Area of expertise: Aboriginal people and HIV/AIDS

Dr. Alix Adrien
Unité maladies infectieuses,
Direction de la santé publique de Montréal-Centre

Area of expertise: Epidemiology, ethnocultural populations

Mr. Don Yeomans
former Commissioner, Correctional Service of Canada
Ottawa, Ontario

Area of expertise: Prison populations

Dr. Peter Piot
Executive Director
UNAIDS
Geneva, Switzerland

Area of expertise: National AIDS programs

Procedure

The panel members were asked to respond in writing to a series of questions on NAS-II after reviewing preliminary reports[1] on all evaluation components. (At the time of writing, responses have been received from eight of the nine members.)

Specifically, experts were asked to provide their "expert opinion on the relevance, success and cost-effectiveness of NAS-II" **based on their review of the study findings.** They were also asked to rate their confidence in each response on a scale ranging from one (not at all confident, completely outside his/her area of expertise) to seven (extremely confident, this is his/her area of expertise). Two of eight responding experts did not provide confidence ratings.

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1. Due to tight timelines for the evaluation, the experts' reviews were solicited in mid-June. At that point, approximately 90 per cent of the data collection was complete. Results were presented in a preliminary, non-integrated fashion, i.e., in a series of chapters providing results on each evaluation component with little integration across components. The final report has thus been substantially modified from the version reviewed by panel members.

Findings

1.a. ***Based on your own point of view*, do you feel there is a continuing need for federal government initiatives in Canada which address HIV/AIDS? Why or why not?**

Panel members unanimously agreed that there is continuing need for federal initiatives in Canada addressing HIV/AIDS. All stressed the need for federal leadership and funding, and most mentioned the need to ensure that national standards are in place. Particular concern was expressed about rates of infection in the injection drug using and aboriginal populations, and the need to ensure their equitable access to prevention and treatment.

Confidence: Mean = 6.4, range from 5 to 7.

b. ***Based on the evidence gathered in the course of this evaluation*, do you feel there is a continuing need for federal government initiatives in Canada which address HIV/AIDS? Why or why not?**

Panel members noted that the study data were consistent with a continued need for federal involvement, but with an concomitant need for refocussing and redirection. It was pointed out that the study data highlight interprovincial disparities, reinforcing the need for national standards and the potential void should federal commitments be reduced. The data suggesting that withdrawal of federal funds would limit the activities of community-based organizations were also cited as evidence in support of the need for a federal role, as were national services such as LCDC. The responsibility of the federal government to aboriginal populations was noted.

Confidence: Mean = 6.2, range from 5 to 7.

2. **How comprehensive and appropriate are the elements of NAS-II? Is there duplication between NAS-II and provincial or local initiatives? Where/what programs?**

Expert panel members saw the elements of NAS-II as appropriate and comprehensive. Potential overlaps were noted between federal and provincial activities and between ATIN and the Clearinghouse, but these were not seen as currently problematic. The need for federal-provincial coordination was emphasized.

Confidence: Mean = 5.8, range from 4 to 6.

3.a. How appropriate is the targeting of NAS-II? The balance between components?

The experts generally felt that NAS-II had been appropriately targeted at the beginning of the epidemic, but had failed to respond to the spread of the epidemic into new target groups, namely IDU's, aboriginals and women. They noted that the data suggested strong support for maintained or increased funding to research.

Confidence: Mean = 5.7, range from 5 to 7.

b. Does NAS-II appear to be reaching its high-risk target populations? Do the NAS-II target populations remain appropriate? Why or why not? For which areas or target groups is/will be the need greatest?

Expert panel members argued strongly, sometimes supporting their arguments with external studies as well as the evaluation findings, that NAS-II is not reaching its target populations of IDU's, aboriginal people and women (or alternatively, that it is reaching them where it is not prevented from having access to them). It was also noted that the current lack of concern about ethnocultural populations may represent lack of ethnicity data, rather than real lack of need for concern. It was noted that MSM still comprise the largest number of new infections. In all infected groups, need will increase for secondary prevention and support strategies. Concern was expressed about the new federal opposition and expected resistance in dealing effectively with high-risk populations. Continued vigilance was urged.

Confidence: Mean = 6.0, range from 5 to 7.

4.a. Based on the study results, and taking into account the many differences between provinces, what do you see as the future *federal* roles in addressing HIV/AIDS issues? Given the current fiscal environment, where do you think the priority should be placed for future action by the *federal* government? That is, which program areas or roles do you feel require lesser and greater attention?

According to these experts, priority for federal roles should go to the following:

- leadership role
- epidemiological monitoring and surveillance, especially of HIV
- ensuring national standards of care delivery
- ensuring equal care delivery to marginalized populations
- ensuring appropriate targeting of community-based programs
- drug monitoring and access
- drug approval process
- education and prevention to groups where infection has increased

- improving effectiveness and cost-effectiveness of intervention
- research funding
- (shared) support to community-based organizations
- transfer of knowledge and information dissemination

It was noted that greater clarification of federal and provincial roles is called for.

Confidence: Mean = 5.0, range from 3 to 7.

b. **What do you see as the future provincial roles?**

Experts assigned priority of provincial roles to:

- epidemiological monitoring and surveillance
- health care delivery
- care/treatment programs
- support of social factors (e.g., housing)
- risk reduction/prevention strategies for target populations
- funding of community-based groups.
- uniform reporting of HIV
- understanding and addressing regional issues
- policing
- public health needle distribution

Confidence: Mean = 4.8, range from 3 to 6.

c. **What do you see as future non-government partners' roles?**

Experts named the following as future roles for non-government partners:

- social supports
- risk reduction intervention
- educational strategies
- palliative care
- volunteer supports for HIV infected persons
- *not* research conducted in NGO's

Experts concurred with evaluation findings that clear roles still exist for the Canadian AIDS Society and the Canadian Association of HIV Research, while the role of the other national partners was less clear. A need to develop more diversified funding sources was identified. The participatory nature of NAS-II was commended, as was Canada's success in involving non-governmental partners in the Strategy.

Confidence: Mean = 5.5, range from 5 to 6.

5. **Given the impacts and effects noted in the findings, do you think NAS-II has been successful in achieving each of its objectives? What in the study results leads you to hold this view? Would any benefits have been achieved if there were no NAS-II?**

☐ stopping the transmission of AIDS

Experts noted the difficulty of attributing any changes in the epidemic(s) to NAS-II versus concomitant trends and influences. Some judged that NAS-II had had significant positive influence among men who have sex with men, others felt that most of that change would have happened without NAS-II, and others were reluctant to speculate. Concern was reiterated about the lack of effect in IDU's and other vulnerable groups.

☐ search for effective vaccines, drugs and therapies

Experts attributed some success to NAS-II in the development of therapies, but very little in terms of vaccine development, generally because of a lack of major funding and the lack of overall scientific progress.

☐ treat, care for and support people infected with HIV, their caregivers, family and friends.

Experts agreed that a major success of NAS-II has been in the ensuring of care and support for those affected by HIV. However, it was noted that some communities may not respond well to the Western medical model in HIV/AIDS treatment, and that alternative approaches should be developed.

It was suggested that without NAS-II, there would have been little opportunity for any of the three goals to have been achieved, and expectations were perhaps unrealistic. It was also noted that the lack of measurable targets or measurement systems for NAS prohibits drawing firm conclusions about NAS-II effectiveness, as does the lack of a genuine, well-funded evaluation of the Strategy.

Confidence: Mean = 5.3, range from 3 to 7.

6. **Based on the study results, to what extent has NAS-II been effective in providing leadership and coordination in developing an HIV/AIDS infrastructure? In contributing to intervention efforts?**

Experts felt that the study data showed NAS-II to have been effective in creating a strong infrastructure and in creating a positive climate of support. It was also noted that the Strategy lacked a clear agenda to the outside community, and that stakeholders were wishing for more communication and opportunities for input. It was also suggested that the evaluation data are typical of federal provincial responses in any domain, not just HIV/AIDS.

With respect to the aboriginal populations, it was noted that devolution will present additional complexities for dealing with HIV/AIDS, and that federal involvement would be desirable on an advisory basis for some time to come.

Confidence: Mean = 4.4, range from 2 to 7

7. **Based on your review of the study findings, do you believe there are better ways of delivering or administering the programs that are now part of the NAS-II? What are they?**

Here, experts noted the evaluation data pertaining to: 1) the lack of transparency in the coordinating body; and 2) the limited communication among stakeholders, especially the federal and provincial governments. It was suggested that accountability for service provision in NGO's must be improved. The need to appropriately adapt program administration and tools for aboriginal populations was also identified.

Confidence: Mean = 4.3, range from 1 to 6.

8.a. **According to your interpretation of the study results, how effective have the research components of the NAS-II been?**

The Clinical Trials Network was cited as an effective component, although limited to the pharmaceutical firms' agenda. Panel members uniformly deplored the level of research funding for HIV/AIDS (and all other research) in Canada, especially in terms of prevention (although this was not unanimous, and the greater difficulty of translating prevention research results into programming, compared to treatment research results, was noted). Lack of information on ethnicity in surveillance data was cited as a major barrier to effective program development, but the contentiousness of research in aboriginal communities (without adequate follow-up and support to deal with problems once they are addressed) was also an issue.

b. **Within the context of international HIV/AIDS research, how valuable do you perceive NAS-II funded projects and activities to be? The overall Canadian HIV/AIDS research effort to be?**

It was generally felt that Canada is a relatively small international research player, but that it had made some notable contributions.

c. **From your perspective, has the Canadian contribution to HIV/AIDS research made a significant difference in terms of international progress: in basic science? in epidemiology? in prevention? in vaccine development? in treatments?**

Some important Canadian contributions were noted in the area of treatment, epidemiology and public health, and participatory prevention research, but none in vaccine development. It was suggested that Canadians generally undervalue the contribution of research.

d. **From your perspective, to what extent has Canada's HIV/AIDS research benefitted people living with HIV/AIDS in Canada and throughout the world? To what extent does Canada's HIV/AIDS research have the potential for benefit?**

Potential benefit is seen to be limited given the level of research activity, although some successes were noted.

Confidence (for all of question 8): Mean = 4.4, range from 1 to 7.

9. **Do the study results indicate that there are gaps in activities or issues left unaddressed by the NAS-II? What are the emerging issues with respect to HIV/AIDS? Should they be addressed by a federal national AIDS strategy? If yes, how?**

Gaps identified had mainly to do with specific target populations: IDU's, aboriginals and ethnocultural populations. The need for a national strategy was re-emphasized, as was the need to more adequately specify the roles of each level of government. Elimination of stigmatization and discrimination and the promotion of tolerance and compassion were also seen as emerging issues, given increased long-term health for those infected with HIV. The need to balance health protection and the right of communities to refuse research and data collection was noted as an emerging tension in aboriginal communities.

Confidence: Mean = 5.5, range from 4 to 7.

10. **Based on the study results, as well as your knowledge of NAS-II, which program areas (prevention, treatment, research and development, community development) do you think will be the most effective over time? Why? Which will be most cost-effective?**

There was considerable variation among experts' responses to this question, with some arguing for treatment and some arguing for prevention, and some for both.

Confidence: Mean = 4.8, range from 3 to 7.

11. **Based on your review of the study findings, and in light of the top priority needs for HIV /AIDS as well as diminishing federal resources, do you believe there are more cost-effective approaches for meeting the objectives of NAS-II? What are they? Are you aware of any other evidence to support these approaches/mechanisms?**

Based on the study data, experts found little reason to suggest that NAS-II was not cost-effective, nor did they suggest more cost-effective models. It was suggested that more rigorous outcomes assessment be undertaken, and that innovative programs such as methadone treatment be evaluated for cost-effectiveness. Alternative models were suggested for delivery of a NAS in aboriginal communities.

Confidence: Mean = 4.8, range from 3 to 6.

12. **In general, based on the study data, do you agree with the conclusions of the evaluation? Why or why not? Are there additional conclusions you would draw from the evidence presented in these studies?**

Expert panel members unanimously agreed with the overall conclusions of the study. However, several noted that because the evaluation data are largely subjective, the validity of the conclusions should be buttressed by additional quantitative findings. It was also noted that the evaluation focussed mainly on individuals and groups who had had contact with NAS-II, with no systematic effort to seek out those who had had no contact.

Confidence: Mean = 5.6, range from 5 to 6.

13. **Do you have any other comments you would like to add?**

Expert panel members made several additional comments about style, the need for more information on program components, as well as about particular concerns in given populations. Several thanked us for the opportunity to participate.